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Abstract

The purpose of this research was to create a grounded theory that would explain what happens inside the mind of a person who has experienced the trauma of a spinal cord injury (SCI). A qualitative research design, featuring dimensional analyses (Schatzman, 1986, 1991), was used to formulate the grounded theory while phenomenological hermeneutics was used to operationalise this process. Six men with SCI, including the author as a participant observer, participated in the research. Participants had between 11 and 19 years of experience with their SCI and their ages ranged from 31 to 45 years.

Two, and in some cases three, interviews per participant were audiotaped and transcribed verbatim. Results were analysed and compared with previous SCI research in order to identify themes and dimensions that were then used to build a model explaining the dynamics involved in the long-term adjustment to SCI.

It is theorised that the pre-morbid personality acts as a filter of meaning to mediate the significance of the losses associated with the accident thereby determining people’s tolerance to stress and their ability to adjust or accommodate to their SCI.

The first part of the model demonstrates the process of “World Collapse” where the trauma from a SCI may greatly exceed the individuals’ ability to cope. When this occurs, affect is automatically stored by the sub-conscious, “Frozen in time,” by a process of “Buffering” and denial, creating the possibilities of psychological and somatic problems.

The second part of the model, long-term adjustment, is presented as a dynamic cyclical process with three basic pathways; namely survival, loss of hope, and hope.
Long-term adjustment is attained through a process of "Defrosting" the affect that has been "Frozen in time" by appropriate use of coping skills, attributes, and personal resources. This process is explained and the implications for counselling practice and future research are discussed.
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I would like to dedicate this dissertation to my mother and thank her for all that she has done for me.

I love you "Ev."
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Preface

This dissertation has been written to inform the reader about the experience of spinal cord injury (SCI). The topic is, Understanding the Trauma of Spinal Cord Injury. To understand the topic I originally planned to use phenomenology and hermeneutics to arrive at a grounded theory to explain the trauma of SCI. However, during the process of analysing the interviews and attempting to integrate the literature on SCI, it became apparent that the information was so extensive and varied that it presented a serious challenge in making sense of the data. Immersion in both the data and literature over a period of four years gradually led to the formulation of a model explaining the male's experience of the trauma of SCI. The main goal of the research was to "get at" or "understand" how a person with a SCI experienced the trauma of a SCI. I was interested in understanding what factors contributed to men with a SCI successfully adjusting to and coping with his SCI.

At the heart of a phenomenological hermeneutic inquiry is the researcher who acts as a vessel through which data is collected and filtered. I broke my neck in an accident on June 1, 1985. In 1986 I wrote a phenomenological account of the accident and my experience of rehabilitation. This account of my accident and rehabilitation is used as a starting point for this research because it, at once, explains my position of prejudice and allows the reader to share the "inside" world of a man who has experienced a SCI.

To facilitate the entry of the reader into this "inside" world of men with a SCI, "insider" terms and language are included in the text. For example, the term "fresh break" is used, which refers to a person with a SCI who has had the SCI for a short period of
time. Also, "quad" and "para" are used for quadriplegic and paraplegic respectively.

There is also a difference in what something means to an "insider" when another insider talks to them and uses a term like "gimp," "crip," or "quad," as opposed to an able-bodied person (ABP) or an "outsider" using the same language. For example, when I meet one of my friends, he sometimes greets me by saying, "Little Clarkie Sloan, you poor little quad, how are you?" From this person, another quad in a chair, it means something much different than if an able-bodied stranger was to say the same thing. From this person it's an acknowledgement of affection and recognition of the trials of living with quadriplegia. However, from a stranger it would be a stigmatising put-down and make me extremely angry. This dissertation is written so as to include the reader as an "insider" to help the reader enter the world of men with a SCI.
CHAPTER ONE

THE ACCIDENT: I CAN STILL SMELL THE DIRT

The gun went off to start the race and all was forgotten. There was a furious surge off the starting line and I was carried along by the energy of the front-runners. I wanted to stay in contact with the first group but I realised the pace they were setting was too fast. I decided to let the first group go and got on the heels of three fellows in the second group and drafted off them. When we got to the two-mile post, our time was about eleven minutes. I still felt good but I realised that this pace was too fast for me. I let the second group go and said to myself, "Run within yourself." I decided to glide, relax, breathe deep and simply finish. I talked to myself and said, "I'm not going to run against anyone else. I'm going to enjoy this run and save some energy for baseball and just use this as a training run."

I had been running the course three times a week for three months, giving me a tremendous advantage because I knew that the toughest part of the course was just ahead. We made a right turn into a twenty-five mile an hour wind. The next two miles were up a gradual incline and there was no cover from the wind. Several people passed me but I let them go. It's strange thinking back on it now because it seemed at some level during the race that I knew this was going to be my last run. I was relaxed running within myself and enjoying the experience of running and racing in the wind. I can remember the wind ripping my hair and almost taking away my breath, and yet, enjoying it immensely. I concentrated on my breathing only focusing on making it till the next telephone post. I decided not to race because it would only burn me out. I relaxed and ran at my training pace, or so I thought.
Slowly I started reeling in runners who had gone out too fast into the wind. I would run on their left shoulder and get in step with them and use them as a shield against the wind. I relaxed my arms and my jaw and breathed deep, staying focused on running within myself. At 6'3" and 195 pounds, I leaned a little extra forward and kept my head down. The wind didn’t seem to bother me as much as many of my fellow competitors because I had run several training runs on the same course in colder and windier conditions. I knew how devastating that long slow incline into the wind could be. The lead group was already several minutes ahead of me but many of the runners from the first two groups were fading. A mile before the finish line there was a half-mile down hill run with the wind at my back, then 800 meters to the finish line. I leaned back and glided down the hill and gathered myself. As I came off the base of the hill, I gradually accelerated and I ran a long, fast kick over the last four hundred meters.

To my surprise I ended up coming in 10th overall and third in my age class. I jogged back to the hill and jogged in with my oldest daughter and my wife. It was the best run I had ever made on only three months of training. I felt great.

I went home, had a hot shower, ate a quick breakfast, put on my baseball gear, and went to the game. I thought, “Okay, play this game and then dash over and make sure everything at the Coca-Cola trail run (that I had organised and was responsible for) is going smoothly.” I remember my friend, Rob, and me sitting on our bench, putting on our cleats. I said, “Rob, I think this will be my last year playing baseball. It's not the same anymore. Everyone is so much younger and all our friends have quit playing and my knees just aren't stable anymore when I run the bases.” Rob agreed.

It had warmed up and it was going to be a nice day up but the footing was still
bad because it had rained really hard the night before. We put some extra shale around
the bases and home plate.

In the first inning I came up with one out and a man on second. I can still
remember the ball coming in. I could see the seams and it appeared as big as a
watermelon. I hit the ball on a line and it bounced once and hit the fence. They were
playing me deep and they tried to get the man at home allowing me to go to second. The
next two batters hit singles and I scored. We were up two to zero. I was batting fourth, so
in the top of the third inning, I got up with a man on second and one out. Again the ball
came in fat as a watermelon. I hit it into the gap in left centre. The fielder cut it off and
threw it into second and kept me on first base. We were up three to nothing. The next
batter hit a sharp single and as I rounded second, the ground gave way and I fell and
scrambled back to second. The next batter hit a single and the third base coach sent me
home. As I rounded third I saw the ball coming in to the catcher. I stopped and got caught
in a run down. The third baseman dropped the ball and I ran for home.

I dove to the inside part of the plate, the catcher caught the ball and knelt down
and blocked the plate. I slid headfirst through the glove and hit his thigh with my head.
My friend said there was a large snapping sound like a tree branch being broken. I rolled
over and tried to get up. Nothing happened. It felt like my knees were up in the air and
my feet flat on the ground, but when I looked my legs were twisted awkwardly and
spread out. I knew instantly what had happened. The umpire came up and I said in a calm
voice, "My neck's been broken, call an ambulance and don't move me."

My teammates gathered around. Rob took one hand, Curtis the other. My arms
started burning like they were on fire. Then there was no sensation and I stopped
breathing. I grabbed their hands harder and time seemed to stand still. I tried to say something but nothing came out. My friends stood in a huddle around me with their heads bowed. I thought I was going to die. I didn’t breathe for over two minutes but it seemed like forever and Curtis started to give me mouth to mouth. Then suddenly I started breathing again. My friends anointed my head with oil and placed their hands on my head and gave me a blessing that I would heal according to my faith.

My wife arrived and rushed over and knelt down beside me. I looked into her eyes. I saw her love and concern for me, but there seemed to be something else, something hidden. I thought it was simply shock at the time. She put her head on my chest and cried. She held me tight and sobbed and cried like I had never seen her cry before. I couldn’t cry. Tears wouldn’t come.

She held me till the ambulance came ten minutes later, but it seemed like an eternity. I can still feel the damp, cool ground on my back, smell the dirt, chalk and sweat, and see the look on my wife’s face as she wept over me. A crowd had gathered around me in a circle with their heads bowed. My close friends were kneeling beside me keeping the crowd back, comforting me. I thought I was going to die and that I was already at my own funeral. It is a memory, a moment frozen in time, that will never leave me.

They took me to the local hospital for X-rays. I can remember lying on the x-ray table wrapped in the stryker board and the doctors standing near me looking at the x-rays and talking in muffled voices. I asked them what was wrong. My doctor told me that I had fractured two vertebrae and that I had dislocated my neck. I asked them what this meant but they wouldn’t give me a straight answer. I asked them to put me into traction
but they said they couldn’t. The body language and muffled voices of the doctors and nurses spoke volumes to me that my situation was hopeless. I felt as if a good chiropractor could have stretched my spine and put me back in alignment. But, that was considered too risky. They would not risk doing anything because they were afraid I would die and they would be liable. The fact that they would not do anything, compounded by the looks on everyone’s face, drove home the fact of the seriousness of my condition. These two things reinforced my worst fears.

I knew that my life as I knew it was over. I had become what I feared most—paralysed—crippled. I also had an overwhelming feeling of “would’ve,” “should’ve,” “could’ve” and a feeling of guilt because the accident could easily have been averted. The catcher could have been two inches to the left. I should have walked in and let him tag me. I could have chosen not to play in the tournament. My wife and I had a big fight the night before and she told me that she didn’t want me to play baseball in the tournament but I stubbornly played despite her begging me not to. I was never expecting the catcher to block the plate because I was out by such a wide margin. I can remember running home and thinking, “I don’t want anyone to get hurt. I’ll try and slide around him.” But, unfortunately for me, it was the first time he had ever played catcher and he was out of position and didn’t need to block the plate. These thoughts ran through my head repeatedly and they still haunt me in melancholy moments. I still wonder what my life would have been like if I had simply had a sore head after the collision instead of breaking my neck.

The doctors said they couldn’t do anything except send me to Calgary. They all had such a morbid look in their eyes and on their faces that I feared the worst. No one
would give me a straight answer. I was convinced I was going to die. Then I was sent by ambulance to Calgary. I started to feel the pain and I was going into shock. The trip was one hundred and thirty miles but it only took about an hour and a half. It seemed as if it took several hours. They wouldn’t let me fall asleep and I was getting thirsty but they wouldn’t let me drink any water. I sucked on ice cubes and fought to keep awake. They pumped me full of Demerol and morphine and everything seemed surrealistic and almost dreamlike. As we raced to Calgary, I thought that I was going to die. I was afraid to fall asleep because I wasn’t certain that I would wake up. We raced to the hospital and I slipped in and out of consciousness desperately trying to stay alive, thinking the whole time that I would be better off dead. The worst thing though was the fear of the unknown. What was going to happen to me? Was I going to live? Did I even want to live?

Intensive Care: Gee Whiz You Guys, That’s My Brains in There

I finally arrived at the Foothills Hospital in Calgary after what seemed like an eternity. The one hundred and thirty-mile trip only took about one and half-hours. My wife later told me they had a difficult time keeping up with the ambulance. When we arrived at the hospital, two nurses and a doctor rushed out to meet us and quickly wheeled me in for some x-rays. They shot me with more morphine. I was in and out of consciousness. Then they wheeled me into the operating room where my mom and dad, my aunt and uncle, my wife and my best friend, were waiting for me. I remember thinking, “What’s my friend doing here with my wife?”

Then suddenly the doctor, with his mask on, was standing over me. He was saying something about having to attach a tong to my head to stretch my spine. The next thing I can remember is the doctor standing there with this huge syringe at least eighteen
inches long, squirting it, and saying this won't hurt. He stuck it into me somewhere behind my ear and it felt like he put it in a long way. Then I had a strange taste in my mouth and my head felt funny. I woke up and my head was vibrating and I could smell burning flesh. I could hear the drill and I could see them drilling into me with a machine that reminded me of a drill press. My head was clamped down and they were squirting me with oil and drilling a hole in my skull. I could smell the bone burning and they kept squirting oil on the drill to cool it. The hot oil ran down my head and onto my neck. I looked up at the doctors and said, "Gee Whiz you guys, that's my brains in there." The doctor momentarily stopped and everyone laughed because I was only semiconscious at the time and I was talking with a bit of a slur. He assured me that I was going to be all right and that this was a standard procedure. They finished that side and then did the other. They took olive oil and rubbed it on the holes, put a washer next to my head, the tongs next and then took a large screw and screwed the tong right to my head. It didn't hurt but each time they turned the screws, I could hear and feel the bones crunch until the tongs were secured tightly to my head. Then they transferred me to a bed that was about waist height and attached a cable to the tongs. They ran the cable over a pulley at the top of the bed and then suspended about 40 pounds on the cable to stretch my spine and relieve the pressure on my spinal column.

I was wheeled to the eleventh floor and put into a room that was kept at ninety-eight degrees because the thermostat in my body had shut down. The bed had a special mattress to support me but not give me pressure sores. There was a sheet under me that was made of silk, it seemed, and was stretched extremely tight. I was naked and they covered me with a thin, light sheet. These precautions were all taken to prevent pressure
sores. I had a tube down each nostril and two tubes down my mouth to help me breathe and drain fluids from my body. I was catheterised to enable me to void my bladder. I was hooked up with intravenous to give me fluids, drugs and nutrition. They also had me hooked up with electrodes to monitor my heart rate. At first they also gave me some oxygen with a mask.

Suddenly all the commotion ended. My wife and my parents left and I was all alone. They gave me something to put me to sleep but I couldn’t shut down. I was afraid to. I thought that if I went to sleep I might not wake up. I couldn’t move anything and I am slightly claustrophobic. I had them take away the oxygen mask because it was causing me to panic. One of my fellow participants, GG, said it best when he described the sensation as “You are in bondage.”

I could feel each beat of my heart. My lips were dry and I couldn’t seem to get them moist. I couldn’t cry because no tears would come out. There was a big pump beside me pumping fluid from my lungs, I lay there and watched it going drip, drip, drip, into a large glass jar. All this time, I was being fed morphine and Demerol. Every two hours five nurses came in and took off the single sheet exposing my naked body. One controlled my neck; the other four turned my body. Usually they only used four nurses but they used five with me because I was one hundred and ninety five pounds. They turned me carefully. Left side, right side, back. Every four hours they came in and gave me medications. Those first few days are like nothing else. I didn’t really sleep, yet I was never really awake.

Part of my confusion and panic during these first few days was that no one explained to me what was happening to me. No one explained that when you break your
neck, your body goes into spinal shock that can last for as long as three months. During this time your entire body and all its systems quit functioning except for an emergency breathing mechanism, which enables you to breathe with your diaphragm. The immune system stops functioning. This is why it is so easy for "fresh breaks" to get pneumonia and bladder infections and get so sick when they are in the hospital. You can't digest food and you lose control of your bowel and bladder function and even your tear ducts stop working.

After about four days I stabilised enough to be moved into a regular room with another fellow named FF. Everything was like a dream at first. I didn't know if I was awake or asleep, or if I was in reality or in a dream. I frequently hallucinated. I can remember one day telling the nurse that I thought I could feel myself emptying my bladder. I was carrying on a full-blown conversation with her. Suddenly my roommate rudely interrupted me. FF said, "Clark." I turned. He said, "Clark, there is no nurse there." I looked back and the room was empty. We both laughed. It had been a hallucination. At that time I was taking a lot of Valium and I found that it really affected me. Another time, FF asked me if those Black guys dancing outside the window had taken his wallet off the heat register. He thought there was a group of street people playing instruments outside our window. I looked at FF and had to remind him that, first, the windows were sealed and, second, we were on the 11th floor. We had to laugh. I was lucky to have FF with me. We became very close. If one of us were experiencing something weird, we would do a reality check with the other, because at this time there was little difference between reality and fantasy.

One of my roommates, HA, complained about an ache in his leg. The leg was
puffy and more spastic than the other leg. The doctor told him he had phantom pain and that the swelling was caused by poor circulation. He had HA wear elasticised hose and recommended he have his legs massaged daily. HA’s father massaged his leg every night for months but the leg stayed the same. Five months later, when HA got out of the hospital, he had his leg x-rayed again and he discovered his leg was fractured. The leg had to be re-fractured, set, and placed in a cast. His spasms decreased dramatically. I had a sensation in my lower left abdomen and a small bump that I complained about in rehab. I was told it was nothing. In a one-year period between 1997 and 1998 I had three hernia operations to repair my stomach. I am certain the hernia occurred during my accident. A minor operation then would have prevented me from enduring three surgeries and my stomach still isn’t right. Many times doctors and nurses tend to stereotype complaints of pain by SCI patients as being caused by neurological damage or that the pain is symptomatic of a psychological problem. Physicians should exhibit extra caution when treating people with SCI because they do not feel pain below the level of the break and serious injuries can go undetected even with extensive x-rays, MRI scans, and physical examinations.

However, the body can give feedback to people with a SCI if they pay attention. I can always tell when I need to have a bowel movement because I get a little light-headed and slightly dysreflexic. The body of a person with a SCI will attempt to warn him of problems by sudden or excessive perspiration or unusual spasticity. In intensive care it is difficult for people with a new SCI to determine if the perspiration patterns or spasticity is normal or if they are a signal that something is wrong because they have no frame of reference for comparison. Compounding the difficulty of interpreting signs is the fact that
people with a SCI in intensive care are in spinal shock and they are on heavy medication. At first I couldn’t recognise the signs of dysreflexia, which were an increase in spasticity, sweating, and a feeling of pressure at the back of my head. This meant I needed to be catheterised. When a person with a SCI complains over a long period of time that something is wrong, many times something really is wrong because the body attempts to find ways of warning you that there is a problem. The problem is that a fresh break does not know what the signs means. It took me several years to read the subtle signs my body gave me before I could link them to specific problems.

There also is the reality of phantom pain. Regardless, the pain and the sensations are real to the person with a SCI and all the health care workers and medical staff should exhibit extreme caution because these sensations may be symptomatic of a serious physical condition. Occasionally these warning signs are ignored as phantom pain when in fact they are feedback about an injury like a fracture or a urinary tract infection.

On the fourth day I was in intensive care, my father came to see me without my mother with him. This was odd because they were always together. My bed was set up at waist height and my father stood beside me and took my hand into both of his and held me tight. He bent over and looked me in the eyes and he started to cry gently. I had never seen my father cry. He told me that he loved me with all his heart from the moment I was born. He said that he thought it was unfair that I had to get hurt. He started to sob and said, “If there was only some way that I could trade places with you, I would.” He put his head next to mine and gave me a tremendous hug. I could feel his tears on my cheek. I never knew the depth of my father’s love for me till that moment. I knew he would do anything for me. My only regret was that it took breaking my neck to be able to find out
the depth of his love and respect for me. This was significant for me because I then knew that my parents had always loved me and would always love me.

My roommate was a twenty-one year old man named FF who also was a C-6, 7 quad. He had worked in the oil fields and was about five feet eleven inches tall and weighed two hundred pounds and he had smoked two packages of cigarettes a day for several years. I had never smoked. The two largest complications people with SCI have in intensive care are pneumonia and bladder infections. The body depends on the intercostal muscles of the chest to expand and contract the ribs to make the lungs work properly. In the case of people with Cervical damage to the SCI, the intercostal muscles don’t work so the body compensates by breathing with the diaphragm and the stomach. When the lungs don’t move much, they fill with fluid and phlegm. Coughing is difficult, if not impossible. Therefore the fluid and phlegm builds up in the lungs and a person can get pneumonia and literally drown if the fluids are not removed. To combat this, tubes are placed down the throat into the lungs and the fluids are pumped out. Each day a physiotherapist comes in and pounds your chest to loosen the phlegm and then manually expands and contracts your lungs so that you can get rid of the phlegm. Each day they test your lungpower by getting you to suck into a plastic device with three chambers in it. Each chamber has a Ping-Pong ball in it. The first time I tried to suck on the device I raised all three balls to the top and held them there easily. My roommate, FF could not even raise one ball to the top. The fact that FF was a two pack a day smoker and I was a non smoker that had run every day made a significant difference in our ability to breath.

The four litre containers by our beds were glass and held the fluid being pumped out of our lungs. The fluid in my container was virtually clear but the fluid in FF’s
container was a thick, black, tar-like residue. When I looked at it, it made me sick. The first time FF saw his container and then looked at my container, he stopped smoking. I believe that my ability to still have a large vital capacity and high oxygen uptake was critical in my rehabilitation. The body needs large quantities of oxygen to heal injuries and to rejuvenate damaged nerves. I believe my body had a huge advantage over many of the other people who become SCI because of all the years of running and weight training that I had done since the age of twelve, and the fact that I hadn’t smoked.

The first week was a blur. It was difficult to tell if I was awake or if I was dreaming, or to tell reality from fantasy. I was a head on a pillow with no sensation or movement from the neck down. I had a tube stuck down each nostril, two tubes stuck down my throat, a horseshoe bolted into my skull and fluids being pumped into my arm. My hands were clenched into a fist and I could barely move my arms. I was catheterised and drugs were being pumped into me. My skin was a dull shade of grey and my body was fighting for life.

While I was lying there unable to move, eat, or feel anything, it seemed as if my mind expanded and filled the room. It was almost as if I became one with the room. I could see, hear, and smell but my other senses were of no use to me. As family and friends started to visit me, I seemed to know what they were thinking. I sensed what they were going to say and I seemed to know exactly what to say to get them to relax. The moment they walked in for the first time was the worst because they would always give me "the look." It was a look that was a combination of shock, love, pity, concern, respect and "I don't know what to say." I would usually break the ice, because I could feel their discomfort, by saying hello and telling them how glad I was to see them. I seemed to
know exactly what to say to put them at ease and make them comfortable. Most of the
time I got them to talk about their problems. One of my friends remarked that he thought
I was helping him more than he was helping me. Every time someone looked at me,
whether it was my wife, family, friends, doctors, or nurses, it was a look that screamed
out, "You are less than you were." "You are someone to pity." This alienation and
separation from the able-bodied population was reinforced by the way I was treated by
everyone including hospital staff and the doctors and nurses. An example of this was
when the nurses came in to turn me every two hours, twelve times a day. They would
come in four or five at a time, often carrying on a conversation about what they did the
night before with their boyfriend or about the fight they had with their husband. It was as
if I did not exist as a person. I was simply part of the job. They would throw back the
sheet exposing my naked body, pause the conversation, one-two-three and flip me like a
piece of meat on a frying pan, put pillows to brace me, cover me up, and move to the next
bed without breaking the conversation. They would do all the beds in the room and move
to the next room as if they had just shifted some furniture.

My wife was visiting me one afternoon when the doctor came to examine me.
After he briefly examined me my wife asked him how I was and what my diagnosis was.
They were standing at the foot of the bed and talking as if I wasn't there. He told her that
I was a complete lesion C-6, C-7 quadriplegic and that I would need twenty-four hour a
day care for the rest of my life. He stated that I would need to live in an auxiliary hospital
for the rest of my life and that I would always need a team of nurses to turn me. When he
left, my wife and I tried to carry on a normal conversation but I knew from her body
language and from the way she acted that the conversation with the doctor had made a
huge impact on her. I began to worry from that moment on about whether my marriage would work out or not. I also believed that somehow I was not going to live in an auxiliary hospital and that I was going to walk again.

I am amazed to this day that a professional could say this with such authority and that he or she would carry out the conversation in my presence. That conversation and the constant reinforcement by all the health care workers that I was never going to recover and that I would live in an auxiliary hospital, I believe contributed to the breakdown of my marriage. It made it difficult to maintain any hope that I had a possibility of any kind of return or decent future. It reinforced all the worst fears that I had about SCI. At that time I didn't know that spinal shock could last up to three months and that it was possible to get a great deal of return even though you didn't have any sensation for the first two months. The doctors, nurses, and physiotherapists are so eager to have you accept the fact that you must accept the wheelchair and your current abilities that it all but eliminates any hope for improvement. This can be discouraging and take away any hope you have and your desire to work on improving your strength or trying to make your relationships work. I remember laying in bed that night thinking that my life was over. I kept thinking that I would never be able to move again, let alone have sex, and that I would have to live in a hospital for the rest of my life. I was very sad because it seemed that all hope for a meaningful future was gone forever.

FF developed pneumonia and became extremely sick. I was a little smug because I could breathe so easily. My turn was coming. I developed a bladder infection. They gave me penicillin but it seemed to act like fuel for the infection. In the next two days, I got worse. I developed a high fever and had a dull ache in my stomach. I could feel my
body weakening even more and the pain was increasing. I can remember thinking, “If I’m not supposed to have sensation from the neck down, then why am I feeling so much pain?” They moved me to a twenty-four hour observation room that had glass windows and was situated adjacent to the nurses’ station. They attached me to a machine that read my pulse and vital signs. The doctor gave orders that I was to have an injection of Talwin every four hours (Talwin is an artificial morphine) at ten, two, and six. They had me back on intravenous injections.

I received an injection at ten and felt pretty good but, over the next hour, the pain started coming back worse than before. Suddenly pain started shooting through me that was more intense than anything I have ever felt. It was as if someone was ripping a dull knife blade through my stomach. This tremendous pain kept happening over and over. It wasn’t even twelve. I called for the nurse. I rang the buzzer but they were doing rounds. No one was at the station and no one came. I started to lose control. I tried to breathe deeply and relax but nothing seemed to work. I was watching the clock and breathing deeply when I noticed that every time the clock ticked the pain would course through my abdomen and my heart would beat. The infection was so severe that every time the blood vessels expanded and contracted in my stomach and bladder, a severe pain would rip through me. The clock kept ticking and the second hand seemed to move in super slow motion. Each minute was an eternity and with each minute the pain got worse. The nurse came scurrying in after about three or four minutes. I told her about the pain. She said that the doctors orders couldn’t be broken and that she could give me some Tylenol #4 but she couldn’t give me any Talwin till two. I was writhing in pain and told her she had to get a doctor for me. They tried to call one of the doctors on call but no one came. I was
desperate and asked them to give me the black pill (like in M. A. S. H.) because I wanted out, I couldn’t take it any longer. They gave me some Tylenol #4 and then they drained my bladder. This relieved the pain for about half an hour but then it came back even stronger. It was still about a quarter after midnight. The clock kept ticking, tick, tick, tick, and with each tick the pain ripped through me like a crescendo, building with each beat of my heart. I prayed to God to let me die. The nurses catheterised me again and the pain subsided to a manageable level but slowly built up again. I watched the clock but it seemed to move slower and slower. They were pouring fluid into me as fast as they could and I concentrated on making it till two. Finally two o’clock came and I got an injection of Talwin and they catheterised me again. I felt much better for about thirty minutes and then it started again. By three o’clock, I was back at full pain. I didn’t think pain could go past a certain threshold but it got worse. I was pleading with the nurses for more painkillers but they couldn’t override the doctor’s orders. I wanted to die and prayed for death to take me. It was the longest night of my life. I really thought I was going to die and that seemed like the best option at the time.

Suddenly the doctor on call from emergency burst into the room and had a hurried exchange with the nurses. He quickly read my vital signs and examined me. Then he injected me with a large dose of morphine. The pain disappeared and then I was regaining consciousness at noon the next day. They had been pumping me with fluids, and giving me large doses of morphine for pain. They had also started injecting me with a special serum they referred to as the golden Cadillac twice a day for three days. Each injection was worth over four hundred dollars. Within three days I was moved back to my room and put back on Talwin pills. A week later I had completely recovered. FF had come
close to not making it through his pneumonia. He was getting stronger but he was still pumping up chunks of tar and black sludge from his lungs.

It was shortly after this that the head neurosurgeon at the hospital came in and visited me. She said that after examining my x-rays, it appeared that my neck would always be unstable. She thought that even if I stayed in the horseshoe for another month my neck would be unstable with a high risk for a future dislocation. She wanted to take an MRI scan of my neck to see if I needed further surgery. That morning I went for a scan. When the pictures came back she explained that I had two choices. I could live with my neck being weak and run the risk of dislocating and breaking it again or she could stabilise my neck by taking two bone slivers out of the iliac crest on my hip and fusing C6 and C7 together with fine stainless steel wire. She also said I had a small cyst or tumour in the spinal column that should be removed because it had the potential to grow and cause me future problems. She said that the operation was delicate and there was a risk of me dying or sustaining further damage to my spinal column. She also said she believed she could do the operation without further complications or damage. She wanted to perform the surgery in two days. That night I prayed sincerely for hours that I would make the proper decision. The next day we had a meeting and I told her that I wanted to go through with the operation. Surgery was set for the next morning.

The next morning I lay in bed and thought about my decision. I realised that I could die in surgery but I also realised that I could not live like this for the rest of my life. I also felt that somehow the operation might change something in my neck and give me more return. I felt that the worst thing that could happen would be that I would wake up with a stable neck and not have to stay in the tongs. I woke up later that afternoon and the
surgeon was pleased with the operation and said every thing went perfectly. I was put back into the horseshoe for three days and then they removed the horseshoe and put a complicated metal brace on my neck. It was attached around my head like a hat made of metal with a plastic liner. Four metal bars connected the hat to a shoulder and chest harness. It felt as uncomfortable as the tongs but at least I got to get out of bed into a reclining wheelchair.

My blood pressure was so low that if they rolled the bed up even a little, I would faint. To combat the low blood pressure and to improve circulation in the body, the nurses would put elasticised stockings and an elasticised girdle that attached with Velcro, on me. Then two male nurses would lift me into a reclining wheelchair. At first I fainted every time they transferred me. The chair was set up so that the back of the chair reclined and the knees ended up higher than the head and the feet were in stirrups even with the knees. I would wake up back in bed. After several attempts I managed to hold on to consciousness and sit in the reclining chair.

They started taking me to Occupational Therapy (OT) and Physiotherapy (PT) each day. In OT, we would put together puzzles, put wooden pegs into holes, and other simplistic, redundant tasks. In PT, I was attached to the pulleys and did some arm exercises. The tasks didn't seem very useful at the time but it was exciting because I was out of bed and doing something. Anything was better than being stuck in bed with the tongs in my head. I even got a bath in the whirlpool. I felt sorry for FF because he was still stuck in bed with the tongs on. About a week later, they took off the monstrous metal brace and put on a moulded plastic brace that had been custom fitted to my neck, around my neck, and attached it with three Velcro fasteners. It was not removed from my neck.
for the next two months.

I still could only flex my arms a little. Day by day I was able to move my arms a little more and then one morning I got the weirdest sensation in my lower stomach area. At the same time I could hear the fluid draining into my night bag from my catheter. I got excited and told the nurse that I could feel myself urinate. She gave me a condescending look and told me it was my imagination. But it wasn’t my imagination. Each day I could tell when I was urinating. I had no control but I could feel it happening. I could feel my penis but not my stomach or legs. I had a full time inserted catheter at this time. The nurse was going to remove the catheter, clean me, and replace it. It hurt when she removed it. I let out a scream and she said, “You really can feel that can’t you.” The nurses were quite excited about this and it meant that I would be catheterised every four hours instead of having a permanently inserted catheter. This presented a problem because I felt a burning sensation each time they catheterised me. I had the worst of both worlds, the pain of catheterisation, and no control of my bladder.

At the end of each daily examination the doctor would stand at the foot of the bed, summarise his examination, and answer any questions. Each day, when he would leave, he would pat my foot and say goodbye. About a week after I felt my penis, the doctor was saying goodbye, he patted my foot and, I felt it. I said, “I felt that.” He said, “You did not.” I said, “I did too.” He said, “Close your eyes and tell me what you feel.” I closed my eyes and he touched my feet. I could accurately tell him when he was touching me and when he wasn’t. Suddenly everyone got excited again. He performed some pinprick tests. I could feel the pinpricks in my toes and around my knees. I couldn’t tell the difference between a pencil and a pinprick but I could feel something. I thought at
this time if I can just move one toe, I am going to walk.

It was the start of July and it was a beautiful summer. One Saturday all twelve boys from the high school basketball team I had coached the previous year came and visited me. They had all signed a small basketball and came to wish me luck. Their parents had come too. I was overwhelmed by the support of my friends and the community. They were fun to visit with and told me that I was in their prayers daily. They all told me how much I had meant to them in their lives. This lifted my spirits. My centre that year was a young man who was six feet seven inches tall and a tremendous person. Six months later, he was riding a bicycle in Japan and got hit by a car and died. It made me realise how important it was to live in the moment and appreciate what I did have. I was glad that I got to see him because he and his parents were the most supportive of all the players, but it made me wonder about the cruel irony of life.

It had been nearly six weeks since my accident and the nurses started feeding me consommé, Popsicles, and Jell-O. FF was still in his metal brace. He had much less trouble sitting upright and didn’t faint like I did. I still had to be in a reclining chair or I would faint. FF could sit upright and even wheel himself a little. He could lift more weights on the pulleys and handle food better but he had absolutely no sensation below the neck. His neck was stable without an operation. We shared a common belief that we were going to get better and walk again.

The summer of 1985 was beautiful. I was in a hot, uncomfortable plastic neck brace unable to move except for my arms. I was over my bladder infection and I was beginning to feel stronger. I was fortunate enough to be able to go outside for a while each day and sit in the sun and smell the flowers and feel the wind in my hair. I had lost
fifty pounds in six weeks and only weighed 145 pounds. I still had a slight greyish tinge to my skin but I was feeling much better. I wasn't strong enough to wheel a chair or do hardly anything with my arms and I had no sensation below the chest except for my penis. Finally, I was getting to eat something even if it was Jell-O, Popsicles, and consommé.

Then one morning in July, with no warning, they came into my room, loaded me onto a stretcher, packed up all my belongings and took me to the General Hospital in an ambulance. You wouldn't think that simply being taken to a different hospital would frighten a full-grown man but I was frightened and almost panicky. I guess it was a fear of the unknown. I had become accustomed to the staff and the routine at the Foothills and I was worried about what was to happen next. As I travelled to the General Hospital, I was filled with mixed emotions of dread and anticipation. At least I was doing something new.

Rehabilitation: I'm Going to Walk Out of Here

When I got to the General Hospital, they took me to the seventh floor of the H block and put me into room four, bed D. I became the quad in 4-D. It was a large square room with four beds in it and two large windows that faced north. Things were different right from the beginning. The first thing the nurse said to me was, “The picnic is over, now you are going to have to work. Things are different here than they are at the Foothills.” This was an understatement.

The first week was similar to the Foothills. The first thing they tried to do was to get me to sit upright in a wheelchair. My blood pressure was so low that if they rolled the head of my bed up two inches, I would faint. They would put elastic stockings and a
girdle on me and then two male nurses would transfer me to an inclined wheelchair. No matter how hard I would try to stay conscious, I would pass out and wake up in bed. They would say, “Breathe deep and flap your arms to improve your blood pressure.” All that would happen is that I would hyperventilate and feel like some grounded Dodo bird and still wake up in bed. At first, this was the all that I was expected to do.

Each day I would try to stay conscious for an extra minute. Every few days they adjusted the angle of the chair closer to ninety degrees. I can remember sitting, breathing deeply, moving my arms up and down. Then I would start to feel a little light-headed. Next, I saw purple spots, then white spots, suddenly a face was leaning over me asking me if I was all right and I would be lying in bed. Trying to sit up and not pass-out was difficult for me. I passed out at least once a day for the next three weeks. FF could sit upright for an hour within a week of coming to the General. My tolerance level increased each day and after two months I could stay up in my chair for eight hours.

My first week at the General was my worst. The three people I shared the room with had weekend passes and left Friday after supper and I was alone. There was only half the number of nurses on the floor each weekend because there was no Physiotherapy (PT), Occupational Therapy (OT), or Recreational Therapy (RT). There was hardly anyone there on the weekends. I still couldn’t move at all. I couldn’t turn in bed by myself and I still needed to be catheterised every four hours.

It was the last Saturday of Stampede week and it was about 28 degrees with hardly any wind. Our room had no air conditioning and the windows were open but no air was moving. It felt like I was in a furnace. I did not perspire from the neck down and I couldn’t move. The only place that I could perspire from was my head. The perspiration
started forming on my forehead and ran down my face in large drops. These slowly
turned to rivulets that ran into my eyes, mouth and into my ears. The sheets around my
head started getting wet. I couldn't move my arms enough to wipe the perspiration from
my forehead and eyes. I became more and more frustrated by the fact I couldn't even
wipe sweat from my brow. The realisation of this fact started to make me feel
claustrophobic. The heat became worse and was suffocating. I tried to reach for the cord
that was pinned to my bed but I couldn't reach it. I called out for a nurse but my voice
was only a loud whisper. I started to panic. It became difficult to breathe. The more I
struggled to call out for help and move, the more frustrated I became. No one came. The
perspiration kept running into my eyes and the heat became absolutely unbearable.
Suddenly, the walls started to melt and move in and out. Then the ceiling slowly started
to descend on top of me and I thought I would be crushed. I let out a yell that surprised
me. I screamed, "Help, save me." Fortunately, a nurse heard me and hurried into the
room. I was out of control and losing it. She took my hand and said, "You'll be OK."
She asked me, "What's wrong." I told her about the heat, the perspiration, about not
being able to move, and that the walls and ceiling were moving. I was also
hyperventilating. I couldn't calm down. She left and said she would be right back. She
came back with a large bucket of ice, two fans, and some damp cloths. She put ice in the
cloths and put them on my forehead and behind my neck and gave me a large glass of
water to drink. Then she put the fans on so they blew right on my face. I still couldn't
calm down. Then she held my hand and sat beside me and talked quietly with me. She
asked me if I had any children. I told her that I had four children. She asked me all about
them. I told her how much I loved them and what they meant to me. She kept me talking
about my children and once I focused on my children, I started to relax. We talked for at least a half an hour and, as I calmed down, my breathing returned to normal and the room quit moving. Whenever I started to feel claustrophobic or anxious, I would think of my children and what they meant to me, take deep breathes, and try to focus on something else besides not being able to move. The nurse was very kind to me that afternoon. She took a half-hour out of her day to help me. She went above and beyond what she needed to do simply because she was kind.

I learned an important lesson that day on how to deal with panic and anxiety attacks. I would breathe deeply and relax and try to feel my heart slow down and think of my children or something I enjoyed, like running. I would use this technique many times in the next nine months to save me from anxiety attacks. The best thing for me though was to get into my wheelchair and wheel in the hall, even though I couldn’t wheel very well. Just the fact that I was moving kept the walls from caving in on me. When I was in my chair, I wouldn’t have anxiety attacks because all I had to do was move.

Within the next few weeks, I was able to sit for an hour without fainting and I learned to transfer with the help of only one nurse. Now my rehabilitation would start in earnest. The plan was to go to Physiotherapy, Occupational Therapy, and Recreational Therapy for one hour each day. The typical day from Monday to Friday was as follows:

<table>
<thead>
<tr>
<th>Time</th>
<th>Activity</th>
</tr>
</thead>
<tbody>
<tr>
<td>6:00</td>
<td>wake-up, get catheterised,</td>
</tr>
<tr>
<td>7:00</td>
<td>eat breakfast, brush teeth,</td>
</tr>
<tr>
<td>8:00</td>
<td>gown, aides for daily living</td>
</tr>
<tr>
<td>9:00</td>
<td>get dressed with assistance</td>
</tr>
<tr>
<td>10:00</td>
<td>until you can dress yourself</td>
</tr>
<tr>
<td>10:00</td>
<td>PT</td>
</tr>
<tr>
<td>12:00</td>
<td>get catheterised, snack,</td>
</tr>
<tr>
<td>1:00</td>
<td>lie down and rest</td>
</tr>
<tr>
<td>2:00</td>
<td>lunch</td>
</tr>
<tr>
<td>3:00</td>
<td>OT</td>
</tr>
<tr>
<td>4:30</td>
<td>lie down, snack, and</td>
</tr>
<tr>
<td>5:30</td>
<td>get catheterised</td>
</tr>
</tbody>
</table>
Each weekday was the same. Every Friday, they served fish and every Sunday, roast beef. Every week followed the same routine. Weekends followed the same pattern except there was no PT, OT, or RT.

There were approximately 24 people with SCI and an equal number of people recovering from strokes on our floor at any given time. Patients had the same requirements for care only they were on different schedules. There were other floors in H block that sent patients to PT, OT, and RT. The organising of all these activities for that many patients was incredible. However, this made me feel like I was a product on an assembly line. I felt dehumanised and I was resentful that I had no input as to when I did things, what I did and how long I did them. I had no input about my medications. The nurses and staff got very upset if I dared to deviate from my appointed schedule.

When the doctor did his rounds, the young interns would go with him and the OTs, RTs, and social workers would make the rounds with him. It was like I wasn’t there they would talk about me but seldom talk to me. They would ask me a question and then decide amongst themselves what should be done. My opinion wasn’t valued at all. They decided the drugs and the program I was put on in committee at my bedside. Since there were four people with SCI in the room and they discussed each case in committee, I knew every intimate detail about my three roommates and they knew everything about me. We had no secrets. In a way this was beneficial because we all knew that we all knew everything about each other. Sometimes I would ask my roommates, “How are you
doing?” and look them in the eye and they would tell me if they wanted to and say, “I’m OK” if they didn’t. Having good roommates really helped me make it through the night.

Each week was the same and soon I fell into the rhythm of the hospital. I felt like I had no control of my life. I found the routinisation very de-humanising. I also resented being constantly referred to as the quad in 4-D. I was bathed every three days in a shower stretcher. Two nurses would dress up in rain gear and rubber boots and put me on a large stretcher made of plastic with holes in it so it would drain. Then they would wheel me into a large shower room and wash me with a long flexible showerhead. It was a pleasure to get showered and feel clean but I felt like an object because often the nurses would talk about other things and I would be lying there exposed and helpless as they washed and sponged me down.

The experience that was the most embarrassing for me occurred during the first three months at the Foothills and the General. This was the bowel routine that was simply referred to as “the routine.” During those first three months, I was too weak to sit on a toilet or even on a commode, which meant that my routine was done in bed. The routine takes between one and three hours. The nurses liked to do it during the day; so often I would miss one of my workout sessions. The nurse would inject the suppository into me and within an hour, I would go into peristalsis and my bowel would completely empty three days worth of feces. The nurses would have me propped on my side with pillows, naked, with a single sheet over me and extra towels behind me. Because there was no fixed time for my routine to work and I was left in my room to wait for the suppository to work. I was extremely lucky because I didn’t smoke and I tried to keep my medication to
a minimum. I ate extra portions of fruit whenever possible and ate bran muffins and brown bread every day. I never had any problems with my routine.

Doing my routine in bed was one of the few things I never got used to. I don’t think time would improve the feeling of embarrassment that came over me each time I had three days of feces come out of me and smear all over me and the bed. It was humiliating. Often the nurses were too busy to come and clean up the mess immediately so I would lay there in the stinking mess unable to do anything but wait. Then the nurses would come in and clean up the mess, sponge bath and powder me, and change the sheets. The nurses were always fastidious about making certain that my bed and I were clean. What bothered me the most about the experience were the comments some of the nurses would make. For example, “Wow, did you ever go.” or “That is a perfect stool.” I really didn’t need to be talking about my shit like we were discussing the weather or what I had for dinner. It always embarrassed me.

I was fortunate because my previous eating habits and activity level allowed my body to still have the capacity to be regular with the assistance of a suppository. FF and several of the other patients on our floor ate too much meat and not enough vegetables and bran. They also took too much Tylenol, antispasmodics and smoked and often became extremely constipated. FF could not do his routine for over a week so they fed him castor oil and then used to use tools to dig out all of his faeces because he was so impacted. FF found this experience to be even more embarrassing than a regular routine.

During that first summer my wife would make the two and one half-hour drive into Calgary, with the children, and stay at her parent’s home. They would drive up Friday night and come in and see me Saturday and Sunday. Then they would drive home.
It was wonderful to see them each week and I looked forward to them coming with great anticipation. The only person that seemed totally unaffected by the fact that I had broken my neck was my daughter who had just turned three. She would sit on my knee and want a ride, give me big kisses, and tell me she loved me this much and hold her arms out as far as she could. I would give her rides all over the hospital and she was so proud to sit on her father’s knee. But, not as proud as I was to have her sitting there giving me hugs. The other children seemed to feel a little awkward, but as the weeks progressed the other children slowly warmed up and treated me almost normally. I was still Dad. My wife was a different story. From the beginning I sensed something was wrong. I thought, at first, that she couldn’t adjust to the fact that I was hurt and that I was physically different. But, as the weeks passed, I realised that there was something that just wasn’t right. I felt that she seemed to be getting more distant and cooler towards me. It felt, to me like she was visiting me because of obligation and not love. I knew very soon after my accident that my marriage was in trouble.

FF had PT with me each morning at 9:00. We were both C6-7 quads and were similar in strength and function. We were both determined to recover completely and walk again. We thought that if we worked hard enough, we would get better. JC had been there for three months and was walking on forearm crutches. He could do 20 sit-ups and had full strength in his arms but his hands didn’t work very well. I was envious of his return, but I thought that if I really worked hard, I could get to where he was. He was a C6-7 quad and his return started by him wiggling his big toe. I thought, “If can just wiggle my big toe I’m going to walk.”
I had two experiences during my first three weeks in the General that had a profound influence on me psychologically and spiritually. The first was a visit to my room from a young man who was about 25 years old. I was sitting in the reclining wheelchair and looking out the window when he came in. I was thinking about the hopelessness of my situation and that my life was over. I think he sensed this as he came in. He introduced himself to me and I will refer to him as K. Four years earlier he had been on a motorcycle expedition from Denver to Alaska. K was involved in a motorcycle accident in Banff in which he broke his back and became a full lesion T-12 paraplegic. He was sent to intensive care at the Foothills and then flown to Denver. He never did make it to Alaska. He told me that he was on a wheelathon from Alaska to Denver to raise funds for the Memorial Hospital in Denver. This was before the Rick Hanson world tour. He was stunning to look at. He sat up straight in his chair and was extremely handsome. He had wavy, shoulder length, light brown hair. His neck was about 20 inches. His chest was about 50 inches and each arm was about 18 inches. He was tanned and looked incredibly fit. He explained that he had wanted to complete the trip he had started four years earlier and had already wheeled from Nome, Alaska to Calgary. He said that he liked to stop at hospitals along the way and talk to the fresh breaks, or newly injured people with SCI. He spent forty minutes with me and told me his story. He said for the first year he sat at home and did not do anything, except feel sorry for himself. Then one of his friends literally forced him to come to the gym and lift weights with him. He found that he still enjoyed lifting weights and started to wheel in some road-races. Soon he was doing marathons. K decided he would finish the trip he started and raise funds for the Memorial Hospital in Denver.
K told me that he had no trouble meeting girls and that he had a really nice girlfriend. He explained that he had a condom attached to his penis and that this was attached to a leg bag with a tube. He said that he had worked out so hard that the nerves seemed to be working their way down towards his legs. He only had to touch his side above his bladder and it would drain. He said that his bowel routine only took him about a half an hour every two days. He said the key for him feeling so good was to get out of the house and start working out again. K was strong, handsome, and confident and was sitting in a brand new sport wheelchair. As I listened to his story and felt his energy, I thought that perhaps there might be a life for me after all.

The second incident that made me feel that perhaps there was a future for me was a visit by LN. He had come in to visit some of the people who had SCI that were on the seventh floor. I was sitting in a manual chair that had surgical tubing wrapped around the push-rims but I could barely move it. The tubing was placed on the rims because my thumbs didn’t work at all and I had to push with the heels of my hands. LN wheeled into my room in an electric chair and introduced himself to me. He told me his story about his diving accident and how he had lost some return because the nurses let his head drop and his neck got broken a second time. He explained how he lived on his own, but that he needed assistance to get up in the morning and to go to bed at night. Otherwise he was quite independent. He said that he was a complete C-5 and that he had a van adapted so he could drive it. I told him that I was a C6-7 but that I could feel myself urinate and feel pinpricks in my feet. LN told me that I would be able to function much better than him and would probably be able to use a manual chair and drive my own vehicle. He said that being able to feel my feet was a good sign this early and that I would probably get more
return and be much stronger than him. When LN left, I felt like there was a chance for a
life. LN had a good job, was living on his own, drove a van, and had been in some
meaningful relationships.

The visits by K and LN had given me hope that there was an opportunity for a
future. I was determined to get as strong as I could, walk out of there, get my job back
teaching, and make my marriage work. I thought to myself that if I could just get a little
stronger, I could live as good a life as these two fellows. The visit by K and LN worked
like a catalyst because, from that day on, I worked out like a man possessed. I stayed in
the workout area every day till lunchtime. In fact, I was late for lunch some days. This
was a bit of a problem for the nurses and the support staff because at first I needed to
have assistance to eat. This disrupted the scheduling of the nurses’ timetables for feeding
and catheterising the people with SCI on our floor. To ease this situation I learned to eat
by using an adaptive strap that was attached with Velcro onto my hand and held a spoon
or a fork in an elasticised pocket. Hospital food is so bland and tasteless to start with that
eating it cold made little difference. What was important was getting those extra two
hours in every morning. The physios didn’t mind helping me because I stayed out of the
way and gave up equipment and moved whenever anyone with an appointment needed
the equipment or the mat. I still couldn’t transfer from my chair to the bed or from the
bed to the chair. This was very frustrating because I knew that this meant I couldn’t live
independently and that I was trapped in bed unless someone helped me. My immediate
goal was to learn to transfer by myself and to stay in my chair longer.

At night I wouldn’t go to bed till about eleven or later and I had fights about this
with the nurses for several weeks. Finally, they would simply leave me till last to
catheter. Then I would lie down and usually stay down. They never understood that when I would lie in bed too long without sleeping, I would get claustrophobic because I was still too weak to move or turn over. I would usually lie down after supper and rest as I saw my visitors. I was fortunate because I had visitors nearly every night at first. My mother and father, my wife's parents, or friends would come and see me. The visits lifted my spirits and made the stay in the hospital bearable. I loved all the cards and the flowers. My parents would often bring me a strawberry milkshake and an order of onion rings from Peter's Drive Inn. HA's mother would bring things like French bread with garlic butter and pate or shrimp salad for all of us. Sometimes we would go down to the cafeteria and have some French fries and gravy. These little treats lifted the spirits and made the time in the hospital bearable. I had some of my former students and athletes that I coached visit me on a regular basis. These visits were a constant source of joy to me. I received an entire shoebox full of Get Well cards and flowers always surrounded my bed. This constant show of love and support helped me be determined to return to my former life. FF's girlfriend and their daughter would visit him every night. JC's wife and his parents visited him every night also. However, several of the fellows on our floor seldom had visitors and I could tell that they were lonely and isolated. I often wondered where their family and friends were.

At 8:00 p.m. visiting hours were officially over but the nurses were usually lenient and would allow visitors to stay till nine, especially if they were from out of town. Once my visitors had gone, I would get the nurses to get me up so that I could wheel and explore the hospital. The General Hospital was a wonderful place to explore. It was three blocks long, eight stories high, and was connected by several hallways and an
underground tunnel. The hospital was built on a hill and was on three levels. The tunnels went under each level and were used to collect laundry and deliver food and supplies. This created one steep ramp and another ramp with a more gradual slope. During the day large electric carts would pull small trains full of laundry, garbage, supplies and equipment to each of the seven buildings. After six o’clock at night however, there is little activity in the tunnels. There was a group of four of us that would go out at about eight each night and sneak into the tunnels. There was a security guard but he had to make his rounds and he usually was not around our part of the tunnel at this time of night. Just for the fun of it we would wheel down the steep hill, and then wheel back up. At first I wasn’t strong enough to get up the ramp myself and so I would watch them roar down the steep hill. The para in the group would pop a wheely and go down this steep ramp on just his back tires. It was spectacular to watch him go down this hill at about 20 miles an hour in a wheely. They would have competitions as to who could coast the furthest without a push on the rims. We were actually having fun and playing. It was also fun because we were breaking the rules. We were caught six or seven times and thrown out of the tunnels and the fellows who drove the carts would honk before they came around corners. I think they knew we were going down there but no one made a big issue of it.

Eventually, I got up the nerve to go down the steep ramp. It was frightening and exhilarating at the same time because I could only brake so much and then I had to lose control and let the chair run at full speed. When I got to the bottom and looked back up the ramp, I couldn’t believe how long and steep it was. I could only make it a quarter of the way up the hill myself and then my arms would start to burn. The para followed me and put his knees into the back of my chair. He said, “Take a short rest and whenever you
are ready." He would only push when I did. I pushed with all my might with him assisting. We got to about five feet from the top and my arms were burning and they simply gave out. I could not move them. They all laughed and he pushed me to the top. We did the same thing about three times a week for several months. It took me two months but I finally managed to get to the point where I could do all the ramps without any help.

One night FF, a quad, a para, and myself were coming back from running the ramps. We got into the elevator and the doors closed. We had raced to the elevators and the para got on first followed by another quad, FF, and me getting in last by the controls. There we were with the doors closed and a quad at the controls. The buttons were too high for me to reach and they were heat sensitive and recessed. My hands were spasmed into a fist and I couldn’t push the buttons. We were trapped and no one was around. The elevator was two chairs wide and two and a half chairs deep. We all laughed. Finally the para had an idea. He grabbed his rims and bounced his chair back and sideways at an angle. FF moved back and I wiggled and bounced till I moved over to where FF had been. We bounced and wiggled two positions clockwise until the para was in front of the controls. It was an important lesson because if I had been alone, I wouldn’t have been able to get out, let alone get to another floor. I learned within the next few days to wrap an elastic band around a pencil several times so I could use it to push the buttons on the elevators myself. I didn’t want to be trapped on the seventh floor.

Soon after that I learned to use my thumb on my left hand to push the buttons. It was at this time that I made my first call on a pay phone. It took me about 15 minutes to figure out how to feed the quarter into the pay phone. The coin slot was up high. I leaned
against the wall and used both hands to put the coin in the slot but I was too slow to dial for the operator. I tried several times and finally braced my hand on the side of the phone and hit 0 with my thumb and got the operator. Success, I had managed to call my wife collect. I had learned to eat, brush my teeth, shave and dress for the most part. I wore loose fitting T-shirts and sweat pants with an elastic waistband. The OT’s had sewn loops on the tops of my socks and my shoes fastened with Velcro. Each day I got dressed more quickly with less assistance. My time went from an hour, with a lot of help, to about 20 minutes without assistance. With each new accomplishment I felt proud of myself because slowly I was conquering my new environment and daily I was gaining confidence.

When I got to the point where I could do the ramps myself, I did them every night. Each night on the seventh floor I would turn on my Walkman, put on my earphones, play rock music and wheel just before going to bed. The hall on the seventh floor was a long rectangle and 20 laps were the equivalent of a mile. The main lights in the halls were turned off by ten and only the nurses’ station night-lights and exit lights were on. Everyone was in bed and the halls were dark, cool and quiet. I would put my earphones on, turn up the music, and wheel at least twenty laps. I would time myself. Every night I would go further; every night I would go faster. After a while I would just wheel for an hour because I would lose count of the laps. I would try to wheel till I was exhausted. Then lying in bed and not being able to turn over or get up didn’t seem like such a bad thing. The shifts changed at ten o’clock so that unless there was an emergency not much happened on the floor from about a quarter to ten till ten-thirty. This is when I liked to be in my chair because I could sneak out the elevator and go down to the
cafeteria and get a snack or down to the sixth floor and visit my friend Pauly. I would also make my rounds at this time and go visit any of the fellows who were still awake at this time. I would visit FF, JC, and HA and run errands for them. Since the nurses were doing their conference, I could sneak into the kitchen and get some fruit juices, milk, a beer (we were allowed two beers a day). Sometimes I would make Cheese Whiz on toast, a peanut butter sandwich or even make a food run down to the cafeteria and get some French fries or pop. Some of the fellows really needed a visit and I guess I needed the friendship also. It was a perfect time to catch up on the gossip and see how everyone was feeling. Our schedules were different during the day and we didn’t get an opportunity to talk to each other much unless we were in the same room. FF had been transferred into the same room as JC so it became a nightly ritual to go and see them and make a treat run. It gave me an excuse to be in the hospital and out and about.

My friend Pauly had the type of MS that would go into complete remission and then come back. Each time it came back it would be more severe and stay longer. Pauly was afraid that this time, it wasn’t going to go away. It was sad to see him getting weaker each week and able to do less while I was getting stronger and able to do more. Soon I would be able to do more than him. I thought I had a chance of getting better because I was improving but Pauly was losing hope. It was hard to watch his body deteriorating week by week even though Pauly tried hard every day in PT. Through it all, Pauly was an inspiration for me and kept encouraging me. He somehow never lost hope and was never jealous of my return, even though his condition was deteriorating daily.

I was always fighting with the nurses about going to bed and when I would be catheterised. Eventually, though, each night I would go to bed somewhere between 11
and 12. Then I would watch TV because I found it difficult to sleep and I could never seem to shut down. It was a combination of the noises and lights in the hall, the nurses coming in every two hours and turning me, but I also had a feeling of not wanting to shut down because maybe I wouldn’t wake up. Whatever the reason, I rarely slept more than four hours a night the entire time I was in the hospital. I compensated for this by having a one-hour nap every afternoon after lunch and I would lie down after supper for a while. It seemed quieter in the hospital in the late afternoons, probably because the shifts changed at two and at six so the nurses wouldn’t bother me at those times.

It was now August and I was able to wheel my chair well and I was getting stronger but I still didn’t have any additional return. I couldn’t transfer by myself but I could sit in a commode for my routine. I was at the stage where I could almost dress myself. I couldn’t quite put my socks on. I think that able-bodied nurses should have to dress with their thumbs taped to their hand so they can’t use them and try to put on stockings. It isn’t easy. This fact was at the core of my first serious blow-up and confrontation with the nurses. The OTs had given orders that we were to dress ourselves before we came downstairs. This was OK for paras and high functioning quads but FF and I had no use of any of our fingers and we still were not very strong at that time. I started at eight o’clock and worked hard till about five minutes to nine. I had been struggling to put my socks on for thirty minutes without success. I asked a nurse, who was in the room at the time, to help put my socks on so I could get down to physiotherapy on time. She said, “No, you have to learn to dress yourself.” I said, “I want to go to physio and I don’t want to be late.” She refused to help me and I got really angry with her. I forget exactly what I said to her but she ended up throwing my shoes and the other
sock in my face and storming out of the room. Shortly after that the porter came to take me to physio so I threw my socks on the floor and put on my running shoes and fastened the Velcro straps and rang for a nurse to help me transfer into my chair. A different nurse came in and helped me transfer. I was fifteen minutes late for physio and steaming mad. I complained to my physiotherapist and after physio, I went to Dr. Blaire (the head physiatrist) and complained about missing some of my therapy even though I had tried for half an hour to put on one sock. I don’t know what Dr. Blaire said to the head nurse but I was never late for PT again. Unfortunately, I had made an enemy of one of the nurses. From then on she only worked to rule on me. I didn’t really care as long as I was at my therapies on time.

My blow-up with the nurse earned me my first visit from the head nurse, who I will refer to as Lorraine, because she listened to my side of the story before she said anything. She talked about Hospital policies and that the purpose of rehab was to get us to do our own aides to daily living tasks. I explained to her my philosophy. I believed that if I could get stronger it would make it easier for me to do these tasks and that for me to miss physio was preventing me from accomplishing this goal. We were after the same goal but we had slightly different agendas. I made an agreement with Lorraine that I would control my temper better and be more polite to the nurses and work hard on dressing myself and doing my aides for daily living. But, sometimes the nurses made it impossible not to lose my temper with them.

There were three male nurses on our floor because sometimes a large male that weighed over 200 pounds or 95 kilos was too much even for two female nurses to transfer. Barry was perhaps my favourite nurse. He was five feet ten inches and weighed
about 260 pounds. He had jet-black hair and wore a neatly trimmed beard. He looked like
the biker from hell but he was extremely kind. Barry worked from six o’clock at night till
six o’clock in the morning. There were six nurses who worked twelve-hour shifts and the
rest of the nurses worked eight-hour shifts. This gave an overlap when the shifts changed.
Barry made things fun because he would get us all down to the TV room Friday night
make popcorn or order pizza, bring an adult movie or something a little racy for us to
watch, and then put us all to bed himself. The female nurses learned not to come into the
TV room late on Fridays because we were just hanging out being guys. Barry had a way
of doing things so that it wasn’t embarrassing or uncomfortable. I didn’t mind him
catheterising me or helping with my routine. Barry died recently at the age of 48 from
Alzheimer’s at the Fanning Centre. It is difficult to fathom the strange twists of fate that
occur in life. I was envious of the physical abilities that Barry and Jerry (another male
nurse) had and now they are both dead and I am healthy and alive.

Peter was about six feet tall, with a slim build, long dirty blonde hair, rough
complexion and glasses. Peter was perhaps the most competent and professional nurse on
the floor. When he catheterised me I didn’t feel much pain. He was considerate and
would do things for you without you asking. He was also on nights and would assist with
our weekend parties. Pete was gay but he was so competent and professional that it didn’t
bother me when he would catheterise me or wash me.

Klause was about six feet two and about 190 pounds. He had light brown hair, a
good complexion, and would be considered handsome by any standards. The first time I
meet Klause was at ten o’clock one night when he came in to catheterise me. He pulled
back the covers and exposed me. I immediately felt awkward and defenceless. I still
could only move my arms but my sensation in my penis was improving steadily. He
didn’t do anything different than any of the other nurses but there was something in the
way he did it that made me feel very uncomfortable. I didn’t feel uncomfortable with
Barry or Peter but Klause made my skin crawl. I didn’t like the way he wiped me clean,
the look in his eyes, or the feel of his hands on me, even though I could hardly feel
anything. I felt violated and I got angry and decided he would never touch me again. Two
days later Klause came in to catheterize me again. He walked up to my bed and went to
pull back the sheet. I said, “Klause, I’m refusing service. I don’t want you to catheterise
me.” Klause said, “Don’t be silly, I’m your nurse tonight and I have to catheterise you.” I
looked him in the eyes and growled, “Don’t you dare touch me.” The viciousness of my
statement surprised him and he took two steps back to the foot of the bed. He had a
strange look in his eye like, “How did you know.” I said, “If you ever lay a hand on me
again, I’ll kill you.” I meant it and somehow he believed me even though I was totally
paralysed. Our eyes were locked for a long moment. He left the room, and 10 minutes
later, another nurse came in and did my catheterisation. Jerry worked on that floor for
eight more months while I was there but he never came into my room to catheterise me
again. Jerry, it turned out, was gay and died several years ago from Aids.

The end of August was approaching and the routine stayed the same week after
week. The food was the same every week. The workouts and therapy sessions were the
same. My visitors started coming at the same time and on the same days and every
Friday, my wife and children would come to see me. The pattern was good because it
gave my life organisation and a sense of rhythm but I found it boring. I was getting much
stronger in my arms and shoulders but I still couldn’t transfer by myself. My sensation
was increasing because I could feel pinpricks better in my feet and legs, hot and cold in my hands and I only needed to be catheterised every six hours. I made certain that I ordered extra food and ate everything that was placed before me and continued to workout extra every day. I wheeled the ramps and wheeled around the floor every night.

At this time FF was stronger than I was. He could wheel faster, climb the ramps better and lift more in PT. I was more flexible and co-ordinated. This made us as equal in ability as two quads could be. We were determined to get better and worked out equally hard, competing daily to see who could do the most. FF, however, wasn’t getting any return whatsoever and was having trouble with spasms. The doctor put him on high doses of Baclofin. During August, I started weaning myself off all medications. The nurses would give me a pill and I would put it in my mouth and pretend to swallow it. I didn’t go cold turkey but I slowly tapered off everything. The first week I mouthed one pill a day. The next week two pills a day until eventually I wasn’t taking any. When I got to the point that I wasn’t taking any pills, I told the nurse that I didn’t want to take any more medication, which is your privilege in the hospital. They didn’t know that I had gradually weaned myself off the Meds and they were quite concerned. I never told them. I just told them to stop bringing me pills. They thought I was some sort of superman because I never had any withdrawal symptoms. It was my little game. I didn’t want to be dependent on drugs of any kind.

It was at this time that I got a new physiotherapist and her name was TW. She was about five feet ten inches tall, with long brown hair, an athletic build, and the biggest and brightest smile I have ever seen. She added a new zest to my workouts because she was an athlete and recognised this in me. She would always push me harder than I could have
pushed myself and at the same time make it fun. I learned to roll from my front to my back and from my back to my front. I learned to crawl around on the mat using my arms and transfer into my chair by myself with the use of a transfer board and a spotter. FF was still stronger but because of the spasms in his legs, he couldn’t transfer nearly as well as me. My left hand was starting to get a little stronger and more co-ordinated to the point where I was starting to eat without the use of any aides. It was awkward and slow but I could do it. FF was starting to get a little discouraged because he worked out as hard as I did but nothing was happening for him in the way of return.

I was a good gymnast and was on the wrestling team in college so I was at home working out on the mats. I was constantly surprising TW and the other physios because I would figure out different ways of doing things they hadn’t seen before. My big goal at this time was to be able to transfer by myself. That would mean that I could get up and go to bed myself and get in and out of cars without assistance. This would allow me independence.

On the chart that TW received from the doctors, the diagnosis for my condition was that I was a C 6-7 spotty lesion quadriplegic. When we first started learning how to roll from my back to my front I was having a difficult time, but I could do it with great effort. On my third time I was running out of strength. She said, “Come on Clark. Roll over. You can do it.” Then she got a big silly grin and said in a voice only reserved for babies or pets, “Come on, Spot. You can do it. Roll over Spot.” Then TW laughed. I laughed and rolled over and went, “Bow Wow.” I became Spot, the wonder dog, because I could do so many tricks. I taught FF how to turn from his back to his stomach and then roll onto his back again. I think being a physical education teacher and a coach for 11
years helped me be creative and invent ways to do the things I needed to do. I knew that I had to get stronger and at least transfer or I would be stuck in bed or in my chair and there would be no life.

Each day I would strain for one more repetition of each exercise. Each week I would increase the weight even if it were only one pound. TW was always there to encourage me. When I thought I couldn't do one more, she would say, “Come on, Spot, one more.” Then she would drag out the one and it became, “Onne more.” This would occur sometimes five or six times after I thought that I had hit my last repetition. I was bench-pressing one day and with each lift she would say, “Onnnne more.” As I tried for the last few, I lifted slower and slower. Soon the one started to sound like “Juan,” the Mexican name. She kept dragging out “One” several more times. My arms were burning and I could do no more so I said in a Mexican accent, “Senorita, Juan can do no more.” TW got a big grin and laughed. Then in a Mexican accent, she said, “Juan is very tired, no.” I said, “Si Senorita, Juan can do no more.” From then on when I reached the end of a set, TW would demand that Juan would do one more and somehow talking in a Mexican accent helped me do more repetitions. I would always lift to exhaustion. If I had a friend visiting me while I worked out, TW took great delight in teasing me and saying things like, “Come on, Spot. You can do it.” Soon everyone was calling me Spot and that became my nickname to the people in physio. I realise now that it is almost impossible to push yourself to the extent needed to re-innervate the nerves. Without the encouragement and spotting of TW, I never could have progressed to the point I did when I left the hospital. I didn’t improve much after I left the hospital because I found it hard to push myself enough to get past the next plateau.
TW could only spend an hour with me every day but she would bring me weights and hook me up to pulleys when she could. The other physios helped when they had a moment. If everyone were busy, I would stretch and tumble on the mats and try transfers. My body was starting to feel alive again. I think it was a combination of not taking any drugs and working in the gym so hard five days a week.

It was August and the weather was beautiful. In the afternoons, when I was in-between sessions, I would go outside and sit in the sun with Pauly and some of the others and enjoy the sun. They would smoke their cigarettes and I would smell the fresh air. We would also go up onto the eighth floor and look out south over the downtown and the Saddledome and bask in the sunshine. From the eighth floor, I could see the Bridgeland pool and I thought how nice it would be to be able to go swimming in the beautiful warm water and suntan by the pool. I didn’t think I would ever be able to swim again. Last summer I swam at that pool every day and sun tanned for an hour. I would also watch the joggers run along Memorial Drive and I would feel a great sadness because I would never be able to run again. I would wonder what was going to happen to me.

I ordered double portions of vegetables and meat at every meal, and ate cheeseburgers and pizzas at night. Surprisingly, the hospital food was starting to taste good to me. My colour came back and I started to put on some weight. FF and I still competed in the gym and we both really believed we were going to get better if we kept working hard. I would watch JC each day with great admiration and respect and with twinges of envy and jealousy. He had a lot of return and could do 20 sit-ups, bench press 100 pounds, and walk using the parallel bars. I was also envious of the abilities of RD. He was a T-12 para and he was my roommate. He was in 4-A, the bed directly across the
room from me. RD was eager to leave the hospital. In August he had hand controls put in
his car and would drive it on his weekend passes. The normal criterion for people with
SCI to leave the hospital and live on their own, is, first that they have a place to go to.
Then they should be able to catheterise themselves, do their own bowel routine, transfer
from their chair to a bed or car, transfer from the floor or ground to their chair, wheel up
steep ramps, hop a normal curb, do all their own dressing and grooming, and be able to
drive a vehicle with hand controls. If a person with a spinal cord injury can do these
things, then he should have no problem living alone and being able to live comfortably. It
is possible to live alone and not be able to do any of these things. However, this requires
a nurse to come in each morning and evening to get him up and then a nurse must come
back each evening to put him to bed. RD was physically ready after two months to leave
the hospital but he didn’t have a job or a place to stay because he had lost those when he
broke his back. RD was so strong that he could transfer on to five boxes, which is
approximately the height of a high table, from the floor. He was also determined. On one
of his weekend passes, he parked in a handicapped stall and when he came back someone
had parked so close to his car that he couldn’t get to his door with his wheelchair. RD
wheeled to the back of his car and, using his arms only, climbed onto his trunk, then his
roof, and slid into his car through the window, backed his car out, loaded his chair and
drove away. RD didn’t seem depressed and simply wanted to get on with life. He always
had a big smile and was fun to be around. He was concerned because he couldn’t find a
place to live and he had no money.

At this time a young nurse (DD) started on our floor as replacement staff when
someone booked off. She was an attractive 22-year-old brunette. RD and DD hit it off
immediately. When the nurses catheterise you, bathe you or change dressings they always pull the curtains closed for privacy. I knew that something serious was going on between them. One night after lights out, DD came into the room and pulled RD’s curtains closed. It was about one o’clock and everyone else was asleep. I was lying on my side, and of course, I couldn’t move in bed because I needed a hard surface to turn over. I was trying to sleep but I heard some muffled talking and I thought, “She seems to be taking a long time with RD.” When I looked over, I couldn’t see any legs under the curtains. My imagination went rampant. They started going out on dates on the weekends and ended up having an intense relationship that lasted for several months. It was shortly after this that RD got a job doing what he did before his accident, namely tuning downhill skies, and moved into an apartment with an old friend. I found this encouraging because RD was back working and had an attractive girlfriend within four months of his accident. There was still a part of me that was thinking, “Yes, but he’s a para.” I was afraid that this couldn’t happen to me.

DD was very attractive and I think she delighted in tormenting me. When she would catheterise me, she would take her time wiping my penis clean with a solvent and I would always get an erection. You can’t catheterise a person with an erection. She would look me in the eyes and then look at my penis and then look at me again and say something like, “It looks as if we’ll have to wait for a minute.” Then she would get everything ready for the catheterisation or go and do someone else until I settled down. Unlike with Klause, I never refused service from her.

Several people with SCI that I have talked to have had sexual experiences with nurses while they were being catheterised. It would only be a natural extension of a
relationship that sometimes takes place between a young man and a young woman over a period of months that develops into love. There were many incidents of romantic encounters between men with SCI and the nursing staff. This is only normal when you have young, attractive men and women thrown into situations where they are together for 30 or 40 hours a week for months at a time. Two people who rehabilitated in the General are now married to nurses or therapists they met in the hospital and several other people with SCI dated or had romantic interludes with their nurses, physiotherapists, or occupational therapists. I felt attracted to several of my nurses and therapists but I wanted my marriage to work and I loved my wife very much, so it was more fun to sit back and watch everything happen around me.

One day in RT, my therapist wanted me to meet her in the gym instead of on the second floor RT and OT room. The gym was in M block, which was one building over and up a sizeable ramp. I wheeled over to M block and barely made it up the ramp and wheeled into the gym. It was the first time I had been in a gym since the accident. I wheeled under the basket and looked up at the rim and thought about how I used to dunk a basketball, and sprint down the floor, and shoot the ball. The lights were off but there was some sunlight shining through the venetian blinds on the windows. I slowly wheeled down the centre of the court and the tears welled up in my eyes. I started to sob uncontrollably and cry as I wheeled. I just kept moving but I couldn't stop crying. All I could think about was that I would never be able to play basketball again and I would cry even harder. It was almost too much for me. The lights came on and DR came in with three people who were mentally challenged. DR knew that I had been a physical education teacher and wanted me to help her with these clients. I think that she also
wanted me to get back into the gym. Luckily I was at the other end of the gym and I took some deep breaths and joined them. DR asked, “Are you all right?” I told her that it was my first time back in the gym since my accident but that I was OK. I had them do some catching and throwing games that would have been appropriate for grade three and then we played some poison ball. They had a blast. The five of us played like grade threes. It was the best thing that could have happened to me because it broke the ice as far as getting me back into the gym.

The Calgary Grizzlies wheelchair basketball team practised every Wednesday night at seven. I started to go to their practices and sit on the side and watch. I told them that I had coached before and that I was interested in being involved. They were polite but didn’t want me to be involved at all. To them I was a weak, low functioning quad and they didn’t know that I had been a successful high school coach for 12 years. This was discouraging to me because even a disabled ball team didn’t want me to become involved with them. This further lowered my sense of self worth. As I watched their practice, I knew I could do a better job of coaching than their coach and the sad part was that they didn’t know what they were passing up. Their practices weren’t well organised and I could see that they needed some help. I quit watching the practices after three weeks because I found it frustrating watching them working hard and going nowhere and not allowing me to contribute. Two years later I was coaching the Lethbridge wheelchair basketball team and we defeated the Grizzlies in a game. It felt particularly rewarding.

The last week in August my wife came up by herself and surprised me by making arrangements in the nurses’ residence for her to stay Saturday night. She made the arrangements so that we could spend the night together. I didn’t know anything about it.
Just before seven, one of the nurses came in and catheterised me. It was odd because I wasn’t supposed to be done till ten. She washed me and then helped me get dressed and said, “There is someone waiting for you at the front desk.” I wheeled down there and, to my surprise, my wife was standing at the nurses’ station with a suitcase and a bag full of my Meds. The nurses and my wife had worked together to surprise me. We then walked over to the nurses’ residence that was in M block and went to our room. The room was tiny and there was just room for my chair to move around the bed. I was as excited as I could be but also I was afraid that I couldn’t actually get an erection, let alone ejaculate. The first thing we had to do was get me transferred onto the bed. I had my transfer board with me but my wife didn’t know how to assist me and the bed was a lot softer than the hospital beds. Consequently I only made it half way onto the bed and we had to struggle for five minutes to get me all the way onto the bed so that I wouldn’t fall off. Then my wife helped me take off my clothes. I was wearing a condom and a leg bag. Then she helped me take the condom off and proceeded to wash my private parts. She undressed and joined me in bed. I could only move my arms. It was frustrating for me because she had to do everything. I managed to get a sufficient erection but no matter how hard we tried or what positions we were in I was unable to have an ejaculation. I felt like a failure. However, I think it was a more difficult for her than for me because it was the first time in our marriage that I didn’t ejaculate. I sensed that she felt that somehow she had failed. It was such an awkward situation and we didn’t even talk about how awkward it was. The worst part of the night was putting on my condom and fastening it to my night bag, then putting about five pillows all around me so I was comfortable, and then not being able to move or hug my wife when she was so close. I think we tried to be together too soon after
the accident but not being able to touch and make love to the person you love for nearly three months is extremely difficult. I think, in retrospect, that I tried too hard and put too much pressure on us to have the sexual part of our relationship re-established for it to have had a chance. I think we felt so awkward about the situation that we couldn’t express our feelings about it to each other. My wife also told me at this time that she could only come down every second week because school was going to start and it was too difficult for her to come every week. I think that her surprise rendezvous ended up backfiring because we both weren’t ready for the reality of making love in a different way than we were used to. It only ended up making me feel inadequate and even more frustrated. I now believed more than ever that unless I had some sort of a miraculous recovery that my relationship wouldn’t work. I could feel it slipping away and I didn’t know how to stop it. I thought that my relationship depended on me recovering. I would lie in bed at night and think, “If I could just wiggle a toe I, would be able to walk.” I would close my eyes and think about wiggling my toes, and try to wiggle them. I thought the only hope I had was if something miraculous happened.

There was a small chapel in the hospital and the elders from my church had arranged to have it for an hour on Sunday. I would meet them down stairs and they would prepare the sacrament and have a lesson for me. It was the weekend after Labour Day and I decided to put everything into the hands of God. I decided to fast for three days and ask God to help me recover. I didn’t eat anything after breakfast on Friday and went for my workouts. I simply didn’t come back to my room at lunchtime and at supper I told them I wasn’t hungry. I drank water after my workouts but then didn’t eat anything or drink anything till Sunday night after my meeting. I prayed for hours Friday night and Saturday
night. I poured out my soul to God that he would heal me. I didn’t think I could make it in the condition I was in. I didn’t want to live in an auxiliary hospital and I thought that if I could get more return that it would make a big difference in my marriage. Sunday morning came and I refused breakfast and stayed in bed and prayed.

I was supposed to meet the elders in the chapel at one o’clock. I got dressed before lunch and went for a wheel so I wouldn’t be tempted to eat and break my fast. I went down to the chapel early and waited for them to come. The Elders came at one o’clock. One of them gave a small talk and then they gave me the Sacrament. I asked them for a blessing to heal. They anointed my head with consecrated oil and laid their hands on my head and gave me a blessing that I should be healed according to my faith. Their fingertips seemed to burn into my head and I felt humbled and unworthy to receive such a healing. I went back to my room and thought about the blessing and prayed that I would heal. Physically I felt the same; nothing seemed to have changed. I lay in bed that night and prayed and desperately tried to move my legs and my toes. Nothing seemed different.

The next morning I was laying in bed and the nurse came in to give me a sponge bath and clean me. As I was lying there being washed I kept trying to wiggle my toes. Suddenly she said, “Did you do that?” I said, “What do you mean?” She said, “Your big toe on your left foot just moved. Did you move it?” I said, “I’ll try to move it.” I looked at my toes and tried to wiggle all the toes on both feet as hard as I could. I watched in amazement as the big toe on my left foot started to move. It didn’t move a lot but I could control my left big toe. Then I remembered the statement that I made that, if I could move one toe, I would walk. The nurse was more excited than I was. She ran out
and brought the other nurses in and I had to show everyone. Each time I moved my toe, I had more control of it and could move it a little further. Then the doctors came in and I had to show them. They gave me some pinprick tests and I could feel more. It also hurt more when the nurses catheterised me. I didn’t dare tell any of them about the fasting and the blessings and I wondered, “Did it really happen or was it a coincidence?” But I knew deep inside that something had happened in the chapel on Sunday. I could actually move my left big toe. I knew at that moment I would walk again.

Later that afternoon Klause, the male nurse I had refused service from, came in and I showed him how I could wiggle my toe. He said, “Forget about walking, you have to accept the fact that you will never walk and accept your wheelchair.” I couldn’t believe how negative he was and how he was trying to destroy my joy and hope. I looked him in the eye and said, “Klause, I’m going to walk out of here.” He said, “You’ve got to accept your chair,” and walked out of the room. This made me more determined than ever to walk out of the hospital and live independently.

That Wednesday four of my friends drove to Calgary from Cardston to visit me. Rob and Curtis, the two friends who held my hand after my accident, were in the group. I told them I could wiggle my toe on my left foot. They wanted to see so I had them pull down the covers. My toe wasn’t moving very much so I tried to really move it and my knee jerked up about a foot and nearly hit them. They all started jumping and slapping each other on the back. Before the end of the night, I could wiggle my toe and lift my knee about a foot at will. By Friday I could get my legs to spasm into extension at will and then relax them. Suddenly I could transfer by myself without the use of a transfer board. My legs, especially my left leg, were coming alive.
In physio they started strapping me onto a tilting table and standing me up. At first, I would faint the moment they got me vertical. Slowly, my blood pressure adjusted to being vertical and I could stay up for 15 minutes. I had been in a wheelchair or laying down for over three months and the first time they put me up vertical, I panicked because the floor seemed so far away. When you are used to having your eye level at four feet and suddenly it is at six feet, it is a shock to the system. In recreational therapy, I was taken to the pool and I started to walk using parallel bars that were waist deep in the water. I started to do leg extensions and ride a stationary bicycle. Then I tried walking on the parallel bars in the gym. This slow progression took place during the month of September. At first I could simply stand up and sit down one time. I worked my way up to three sets of ten. Then I worked on taking one step. TW would push my chair behind me so I could collapse into my chair when my legs buckled. Each day I would walk until I collapsed trying to go one more step than I had the day before. Soon I could do one entire length. Early in October I got to the point where I could walk one length of the bars turn and walk back without spotting. I then slowly worked my strength to the point where I could do ten repetitions of one length at a time. 

It was the second week in October and I was able to transfer myself without the use of a transfer board. In Occupational therapy they made moulds of my hands and made some plastic glove-like holders that they attached to the handgrips of my new forearm crutches. My hands had absolutely no grip and I couldn’t hold on to the crutches unless I was strapped in somehow. I would put my hands in the plastic holders and grab the handles as hard as I could. Then they would fasten the plastic device over my hands and the handles with Velcro fasteners. I had to be careful when I fell because I couldn’t let go
of the crutches and if I fell awkwardly, I could break an arm. I had no trouble standing up
with the forearm crutches but it was almost impossible for me to take a step because they
weren’t stable like the parallel bars. I had no balance and I would fall whenever I tried to
walk. It was difficult to trust the spotters because once I started to fall there was about
160 pounds of dead weight.

The physios couldn’t spend the time with me that I needed to practice walking so
they got one of the female porters to spot for me when she had time. Her name was Olga
she was a big buxom German woman. She was five feet eleven and about 250 pounds.
When TW and the other female physios would spot me when I tried to walk they would
protect my head and cushion my fall by slowing me down but I would still hit the floor
pretty hard and sometimes it would really hurt even though I had diminished sensation.
The first time I walked with Olga, I made about two and a half steps and I fell forward
face first. My face was about six inches from the floor and suddenly I stopped before
anything hit the ground. Then the next thing I knew I was standing again. I told her that
she would hurt herself if she tried to catch me and that she should simply cushion my fall
to the floor and make certain my head didn’t hit the ground. Olga said, in her heavy
German accent, “I am strong and I do not want you to get hurt.” It made a big difference
to me to have Olga spot me when I walked because I trusted her and I never fell to the
floor again. When I would stumble or start to fall, she would steady me and then we
would continue. Within a month we were walking one complete lap of the hall. It was
easy to push myself because I knew Olga wouldn’t let me fall and hurt myself.

Two weeks after I moved my toe I was laying in bed and my arms started to
tingle. Then they felt like they were on fire and burning. They felt very much the same
way they did on the day of my accident. This continued for several days but I had no new
return of function in my arms or hands. One morning I woke up and wanted a nurse for
some reason. The nurse on the night shift had forgotten to pin the string, to call the
nurses, to my sheet. It was hanging against the wall behind my head. I was still half-
asleep. I reached out with my left hand and grabbed the string and rang for the nurse to
come. It took a few seconds for what I had just done to sink in. I tried it again and I could
do it because now I had some triceps in my left arm. It was the strangest sensation to be
able to do something one day when the day before I couldn’t. Things didn’t come in
gradually or gently. Suddenly I could feel or do something that I couldn’t do the day
before.

A week later I woke up and my chest and upper abdomen felt like cold blue steel.
I felt like something was there all of a sudden. I could sit up, without any difficulty and
transferring became no problem at all. My left hand started to get stronger and more
dextrous and slowly I became left-handed. As I used my left hand more, my thumb
started to work to the point that I could grasp things and put on socks that didn’t have any
loops on them. It was the beginning of October and I thought that if I could continue to
improve and get more return at the same pace, as things were coming back, that I would
be running in marathons within a year. After my chest came in I didn’t experience any
other major returns but I did get stronger with what I had.

In September I was allowed to go out on weekend passes. We made an
arrangement that my wife would come and see me every two weeks and on alternate
weeks, I would come home for the weekend. My friends and the people of Cardston were
wonderful. On Friday evenings, someone would volunteer to pick me up and drive me
home. Then on Sundays, someone else would pick me up and take me back to the
General. The hospital staff arranged for me to get some portable ramps to take with me so
I could put them on my front stairs and get into my house. The first time I went home my
wife couldn’t handle me on the ramps and I fell out of my chair down the stairs and onto
the ground. I wasn’t hurt but she had to get my next-door neighbour to help get me into
the house. When I got inside, I realised for the first time how hard it was going to be to
live in a chair in the real world. The children had left their shoes by the door and there
were some toys in the hall. These made it difficult to wheel and I couldn’t bend over to
pick them up in September. When I first went home, I couldn’t stand on my own and the
cupboards, sink, and countertops in the kitchen made it almost impossible for me to help
with any kitchen work. It created a frustrating situation because I couldn’t help with any
of the preparation of the food and I was so slow and weak that I was simply in the way
when the dishes were done. I would sit at the table and watch while everyone else set the
table, prepared the food, cleaned up and did the dishes. Everyone went out of his or her
way to do everything for me. If I tried to help, it seemed that I was in the way because of
the size of my chair and the fact that I couldn’t do things very quickly. I decided to
simply stay out of the way. This pointed out to me at the time that I was in some way
deficient, inadequate, or helpless. I felt like I couldn’t contribute. I kept thinking about
how I used to be able to cook and clean up before my accident. The problem was that
before my accident I only cooked and cleaned up on Sunday and rarely did any
housework except vacuum on the weekends. Somehow not being able to do any of the
work was extremely difficult for me. It was the fact that I didn’t have the option to do
things, or not, that bothered me more than missing doing the actual task, for example 
dishes.

In the evenings we would have friends over and we would play board games or 
watch movies. Then we would go to bed. We had a waterbed with baffles in it but I 
needed a firm surface so I could use my elbows to turn. I still had to wear a condom and 
use a night bag. I didn’t sleep well so consequently my wife didn’t sleep well either. I had 
to struggle to get out of the waterbed and transfer because I had nothing solid to pivot on. 
There was no room for me to turn my chair in the bedroom so I would have to back out. I 
brought a shower chair home and put it in the tub but getting in and out of the tub and 
showering was an extremely difficult task compared to my shower chair at the hospital. I 
also couldn’t turn my chair in the bathroom.

With all the difficult transfers, it seemed that I would blow an unusual number of 
condoms and wet my pants, further adding to the frustration. Everything was so much 
more difficult in the real world and seemed to constantly bring to mind the fact that I was 
disabled. The environment in my home was not wheelchair friendly.

Saturday night my wife and I would make love but it seemed as if something was 
missing. This made me feel even more inadequate about my sexual prowess than I had 
before I started coming home. There was a real difference in how we related physically. I 
was unable to be the aggressor and my wife didn’t seem to like that role. My fingers on 
my hands were bent into a fist and I had little touch sensation in them. From the neck 
down I had limited touch sensation so most of my excitement had to be generated 
psychologically. This was difficult because our normal sexual roles were reversed and I 
was so concerned about my sexual abilities and that I couldn’t please her. My wife was
becoming more distant with each visit and appeared to be doing everything out of obligation and not love. These factors made me feel inadequate and I couldn't get excited and get an erection. This, in turn, seemed to further distance my wife, preventing her from becoming aroused. This vicious cycle was amplified the more we both tried to make it work. This is one situation where trying harder only makes things worse. I managed to get an erection and we made love but I couldn't ejaculate. I knew from my classes on SCI at the hospital that most people with SCI can’t achieve an erection and only about five percent can achieve ejaculation. Knowing this did not seem to lessen the disappointment of not being able to consummate my lovemaking with my wife. I think that my wife felt that in some way it was her fault that I was unable to ejaculate and that she in some way had failed me and was in some way inadequate. This was not the case.

We were required to go to SCI classes once a week for eight weeks. The classes focused around the physiological changes that were occurring in our bodies and a great deal of time was spent on sexuality and relationships. Each person on the floor was supposed to attend with his significant other. I think that the basic idea and the intention was good; however, my wife couldn’t come to the classes and the people teaching the course made the assumption that we all needed and wanted the same information. Nothing was further from the truth. JC and his wife, for example, were completely turned off by the course and quit coming. They both felt that the instructors made too many assumptions about what they needed to know. They didn’t feel ready to try and continue their sexual relationship at that time and would have preferred to have some guidance in a one on one situation. Many of the people, including myself, were too shy to talk about what they really needed to know because they were afraid to ask certain questions in
front of the group. My wife couldn’t come to the classes and really didn’t want to so the classes were pretty useless for me. Even if I understood everything, it didn’t do me much good because my wife wasn’t interested.

On Sundays we would go to church as a family but this was quite an ordeal for my wife because it was like she now had an extra child to look after. Not only did she have to get the four children ready but she had to help me dress and I also tied up the bathroom for an extra thirty minutes. Getting me out of the house was difficult. It took my wife and my fourteen-year-old son to lower me down the ramp. Then I would transfer into the front seat of the car and my wife would have to fold up my old Everest and Jennings wheelchair and put it in the trunk of our Pontiac. This was no small feat because my chair was big, bulky and weighed over forty pounds.

After church we would come home and fight up the ramp and have our Sunday dinner. Then someone would give me a ride back to the General. I would be drained physically and psychologically when I got into bed Sunday nights. I would lay there and think about the weekend and all the good times I had with my children and my wife but, at the same time, I had this terrible feeling, a premonition, that my marriage was in trouble. I thought that, if I could simply get walking, get more return, and function better, that everything would work out.

During the month of September two new people moved onto my floor. PA moved into bed 4-B beside RD in our room and TT moved into FF’s room. PA was 30 years old and had a severe attack of Multiple Sclerosis. His condition was rapidly deteriorating. When he first arrived PA could walk for a short distance with two canes but he needed to be catheterised. As the weeks progressed, PA’s condition slowly deteriorated to the point
where he had to use a wheelchair exclusively. PA would get extreme spasms and it didn’t seem to matter how much Valium or Baclofin they gave him, PA would have uncontrollable spasms and cramps that would rack his body in pain. It would usually take at least two nurses to stretch out his limbs and bring him relief. They would inject him with some Demerol, stretch him, and tell him to breathe. I was saddened by his deterioration. Like Pauly, he was going downhill and I was steadily improving and getting stronger. I felt the same way about FF, and some of the others. I had a sense of guilt that I was receiving so much return and could walk on crutches while many of the others were receiving no return and couldn’t even transfer. I knew that that they were happy for me but at the same time I could sense that they wondered, “Why is he getting return and not me?”

Towards the end of October I was having my daily nap at about 2:30 when PA let out a terrible shriek. He doubled up into a tiny fetal position and his body was vibrating. He couldn’t move so I rang the nurse. A nurse came in but she couldn’t move or straighten any of PA’s limbs. The nurse called for backup and immediately three more nurses, two males and one female came rushing in. They tried to straighten his limbs, two on one limb at a time but nothing could straighten PA’s arms or legs. By this time every muscle in his body was cramping and he was in excruciating pain. PA started crying and begging them to do something to stop the pain. The charge nurse came in at this time and stood in the middle of the room folded her arms and said, “What kind of a man are you? Quit your crying. What are you, some kind of a wimp?” She kept it up and told him that real men do not act like he was and that he was weak. This went on for several minutes. She was the charge nurse on the floor that day and had worked on this floor for many years. Finally, I couldn’t listen to
her any more. I yelled in my loudest voice that had been developed in 12 years of teaching Physical Education outside, “Who the Hell do you think you are?” She turned and looked at me. I said, “It’s easy for you to stand there and make snide remarks about his manhood. I don’t see you in bed totally paralysed with MS and contractures so severe four nurses can’t straighten one arm. Why don’t you just go get something and knock him out and put him out of his pain?” I used a lot of foul language and I questioned her ability as the charge nurse. She couldn’t believe anyone would ever talk to her that way because I even threatened to report her to Dr. Blaire if she didn’t do something besides question his manhood. I glared at her. She looked around the room for support but everyone else had wished they had said what I said to her. She stormed out of the room and came back with a large syringe of Morphine and knocked PA out. Then they gently stretched him and broke the spasms and the cramps. I gained a tremendous amount of respect from my roommates and the other four nurses because that is what was needed at the time, not questioning his manhood. Of course, I had been there, I had experienced pain that made you want to give up and die and that made you cry uncontrollably, where breathing and relaxation had no effect. Perhaps she had never experienced pain like that.

I had another visit from Lorraine, the head nurse of the floor, the next day. I don’t know what the charge nurse had written about the incident from the day before but I already had a reputation as being difficult to get along with. Lorraine told me I had to control my temper and be more co-operative. I told her that I wasn’t the one she should be talking to and that if the same thing were to happen again that I would do the same thing without any hesitation. I was not about to lie there and listen to somebody needlessly berate one of my roommates. If she didn’t like it, I really didn’t care. I told her that all I wanted to do was get
better and if there was anything that I could do to help, I would. She got a bit of a funny
look in her face and said, “Let me think about it.” I believe Lorraine reprimanded the
Charge Nurse the next day because from then on she was always rude to me and I stayed
out of her way. I had made another enemy. The problem was that she was in charge of
administrating and passing out medications at night so we developed a working truce.

TW and the other female physiotherapists knew that I had broken my neck
playing baseball and that I had been a high school physical education teacher. They had
formed a team called the P. I. G. S., which stood for physiotherapy, internal medicine and
general surgery. They were an all women’s team and they played every Thursday night in
August and September. They got me to coach them and arranged for a Handi-bus to take
me to the games and pick me up. It was my first excursion out of the hospital. It was
extremely difficult to wheel on the gravel and on the grass and the women would have to
wheel me out to third base so that I could coach them. It was difficult to sit in my
wheelchair and not be able to play but the women I was coaching were a lot of fun. They
would each have a beer or two and the PIGS would verbally abuse the other women’s
teams. The games were a social event and not about winning but the PIGS liked to win
too. In mid-September I was getting ready to go to our last league game before the play­
offs when I noticed the weather was getting a little cooler. I put on a sweater and took a
light jacket with me. When I got there the sun was still shining but there was a cool wind
out of the north and there were big banks of black clouds rapidly moving in. The game
started at five in the afternoon and by the third inning the clouds had obscured the sun
and a light drizzle had started. I started shivering and my hands started to turn blue. The
temperature dropped to about five degrees Celsius. I was trapped because the Handi-bus
didn't come back for another hour. The drizzle wasn't bad enough to cancel the game so I kept coaching and I didn't want to appear weak. It got darker and the wind picked up but the rain stayed away. We finished the sixth inning and we were collecting all the equipment when it started raining hard. They had to push me across an entire field about one hundred yards to the Handi-bus. I got thoroughly soaked. I was so cold I didn't feel cold any more. When I got back to my room, the nurses peeled off my wet clothes and I went to bed but I couldn’t stop shivering. The nurses heated some sheets and wrapped me in them. I stayed in bed all night and the next day. The nurses kept wrapping me with heated sheets every two hours but I couldn’t stop shivering or get warm. It took two days before my feet would get warm. I didn’t catch a cold but I learned a valuable lesson.

When I was told that my body assumes the temperature of its surroundings in our SCI classes, it never sunk in. Now I realised that I needed to take extra precautions for cold weather because the thermostat in my body didn’t work properly. I was fortunate that I hadn’t contracted pneumonia and become extremely ill. I only felt the cold on my arms and on my head and shoulders I didn’t realise how cold my feet were.

My birthday is on October 28th. My wife was coming up that weekend and said she wanted to take me out for dinner. I was excited. She picked me up at seven and said we were going to meet some friends for dinner at the Delta Bow Valley. When we got to the hotel, she had a little suitcase and a bag full of my Meds from the hospital. She had reserved a room at the hotel for us and arranged to secretly get my Meds from the nurses. I got really excited that she had gone through all this trouble for me. We went up to the room and ordered some food and watched some TV. My wife put on her nightgown; I slipped out of my clothes and got into bed beside her. I put my arm around her and tried
to snuggle but she drew away and kept watching TV. I moved over again and tried to
cuddle her and give her a kiss. She pushed me away and said, “I thought I could do this
but I can’t.” I was stunned. I said, “What do you mean? You go through all the trouble
of reserving a room and you don’t want to cuddle or make love or even be with me.” I
tried to get closer but she pushed me away. We argued because I couldn’t understand
what was going on. Finally she said that I would have to sleep in the other twin bed. I got
dressed and transferred into my chair and went to go out the door. It was two in the
morning by this time and I had no clue as to how I was going to get back to the hospital
but I wasn’t going to stay there. My wife was crying and put her arms around me from
behind and said, “Please stay; do not leave.” I decided to stay but I felt like I should have
gone. We slept in separate beds that night and I didn’t sleep at all. The next morning she
brought me back to the hospital. It should have been one of the best birthdays of my life
but it ended up being one of the worst experiences of my life, being rejected by my wife.

Shortly after my birthday, Lorraine came in and asked me if I was serious about
my offer to help. I told her that I was. She told me that she would like me to act as a
mentor to the freshly injured quads that came in. She said that she had a young 19 year
old who was coming in from the Foothills and that she would like to put him in the bed
next to mine and have me look after him and coach him. She said she realised that I was a
teacher and that I could act as a role model for the fresh breaks. I was excited because
this made me feel useful because I could actually help someone. That afternoon a young
man named RR was moved into the bed next to me. He was very sad and having a lot of
trouble breathing. He was experiencing some of the panic attacks I had in my first week
at the General. He was also experiencing a break-up with his girlfriend. I took him under
my wing and tried to help him. I think that this helped me greatly because now I wasn’t focused only on myself. RR saw how hard FF and I worked out and how much we could do. FF could transfer using a transfer-board and was extremely strong in his chair. In fact, he could still wheel harder than I could at this time. RR worked hard and tried to catch up with us. Soon we had him running the ramps under the building. I showed him how to flip over on to his back and how to use all the aides.

TT was a young man 21 years old. He was six feet tall and had a slender almost anorexic build. His hair was brown and hung down to the middle of his back. He had been a passenger in a car that crashed at about 100 miles an hour. We saw a picture of the car on his wall and it was smashed up into a little ball and I was surprised anyone could have survived an accident in that vehicle. TT had broken his back at T-5 and at L-1. The doctor told him that both breaks were complete lesions and that he was going to be a complete lesion paraplegic. TT was uncooperative with the nurses. Some days he would refuse to dress. When they gave him his shoes he would throw them at the nurses. He was always late for his workouts and when he got there he didn’t do much. He had strong arms and would come and wheel the ramps with us. Each day he would find a secluded spot in the tunnels and smoke a joint. He would drink his two beers every day and go out on binges of drinking, taking drugs, and watching the strippers with his friends on the weekends. TT put no effort into his rehabilitation at all. In mid-November TT suddenly was able to get knee jerks on both legs and was getting some return in his stomach. It is surprising what a little return will do to a person’s behaviour. TT started to go to all his workouts on time and really try. In fact, he would stay extra and try to sit up straight in his chair and he started working on his legs extra hard. He still liked to sneak out and smoke a joint or two each
night. Sometimes I think that the pot might have helped him in some way. He became consumed with walking. TT and I had different return. His flexors in his knees and hips worked but his extensors didn’t work well. My extensors worked well but my flexors in my knees and hips, especially on the right side, didn’t work well. This meant that I could stand but I dragged my feet. TT couldn’t stand very well but he could lift his knees with ease. TT had full arms and hands and his trunk was coming in fast.

When TT suddenly started getting return, FF’s attitude deteriorated. He didn’t mind it so much when I was getting return because I was working so hard but when TT started getting massive amounts of return when he had broken his back in two places, it was too much for FF. The relationship with his girlfriend was deteriorating rapidly. It was sad to see. M was in love with FF and was doing everything to make it work. She came in every night, with their little girl, for three hours and wanted FF to come home every weekend but FF was pushing her away because he could not deal with the fact that he wasn’t improving and could not have sex with her the way he used to. HA was doing the same thing to his girlfriend. They were both pushing the people away from them who loved them the most. It was ironic because in my case my wife was pushing me away. It seemed that the harder we tried to make it work, the worse things got. FF started to get bitter. His spasticity got worse and he started to take massive amounts of anti-spasmodics and Valium. He started smoking again and drinking large amounts of alcohol on the weekends. He didn’t work out as hard. It was as if he had lost hope. He became discouraged. It made me feel guilty in a way because I was getting so much stronger. He started smoking again, drinking more, and would get drunk on rum and sleep on the couch when he went home.
My bowel had improved to the point that I didn’t need a routine any more. I could wheel into the bathroom and transfer onto the toilet and have a bowel movement that was almost normal. If I were rating it at that time it would have been at 90 percent. I couldn’t control my urinating but I could tell when it was going to happen and empty my bladder into a bottle or the toilet. I decided to try and train myself. I went cold turkey and started going without a leg bag or a condom during the day. I could only go about an hour and then I would have to go to the bathroom and urinate. I only had about two minutes from when I felt I had to go till my bladder would release. There seemed to be no pattern. Sometimes I could go an hour and a half with no problem and other times I would have to urinate every half-hour. This made it difficult to walk because the walking seemed to trigger a release. I would get half way down the hall and I would trigger. Before I could get back to my chair or walk to the nearest washroom, I would wet my pants. It didn’t seem to matter how often I wet my pants; it would still embarrass me. I also resented the fact that I had to go and change and this would take a minimum of one half hour. I would wet my pants at least once a day for the next month. Each day I tried to hold it longer after I triggered when I was walking until I could walk for about five minutes after I felt I had to go, without an accident. By Christmas I was able to sleep without being hooked up to a night bag.

Training my bladder was perhaps the most difficult thing that I did in rehab but I was determined not to have to wear a condom and a leg bag the rest of my life if I didn’t have to. I kept working on holding my water longer and longer until I could hold it for two hours between urinating. From that December until now I have not been able to sleep for more than two to three hours without getting up to go to the bathroom. I haven’t slept
for seven hours straight for over fifteen years. As much as I would like to have a good
night’s sleep, the alternative of being hooked up to a night bag and losing my freedom of
movement and sexual spontaneity didn’t seem worth the price of a good night’s sleep. I
realised that unless I tried to get my bladder to work and consciously tried to extend the
time between urinating, I would never improve. It seemed that I wasn’t improving at all
but by December I had much better control, but I would still get caught in no man’s land
half way between my chair and a washroom and have an accident. Nothing is more
discouraging than holding on and controlling yourself till you get to a toilet and then not
being able to undo your zipper, because of your bad hands, and having a steady stream of
liquid run down your pants. Once I broke my concentration of holding on and had to
focus on another task, then my body would release and I would have an accident. This
causd me a lot of embarrassment and dirty laundry in the first three months I went off
the condom and the leg bag.

The issue of the bowel routine and urinating consumes much of the time, energy
and thought process of a person with a SCI. It seemed that these issues would come up in
almost any conversation with a person with a SCI. The reason for this was that if these
functions were not working properly, then you would soon become seriously ill or
become dysreflexic. If your bladder gets too full, then it can cause your blood pressure to
rise. If your blood pressure rises too much, then blood vessels in your brain and heart can
burst. For example, if you were supposed to be catheterized every six hours and you
drank two litres of water during that time because you had a bladder infection, it would
be possible for you to become dysreflexic. When you become dysreflexic, you get
flushed, start to sweat, and you start to feel dizzy and, all of a sudden, the back of your
head feels like it is going to blow off. It’s like when you drink a slurpy too fast on a hot summer day only it doesn’t go away and it hurts much more. FF was sick with a bladder infection one night when I was visiting him. He was feeling very dizzy and was beet red and didn’t look well. I rang for the nurses because I knew he had to be catheterized immediately, even though he wasn’t due to be catheterized for another two hours. The nurses came in and I said, “I think FF is dysreflexic.” They took one look at him and put the blood pressure cuff on him and took his blood pressure. It was something like 220 over 180. He was close to blowing up and having brain damage or dying. The nurses said I would have to go, closed the curtains and immediately catheterized him. When I came back fifteen minutes later, he was fine. If they had not catheterized him, he could have had a stroke, serious brain damage or perhaps died that night. The blood vessels in his brain would have exploded. The bowel is not quite so critical, but if it is not emptied every three days it can become impacted and it becomes difficult to unplug. The worst situation of this I saw was with HA. He had an impacted bowel for ten days. They tried everything. They tried all the different suppositories, they fed him mineral water and all the different laxatives, but nothing worked. Finally, Barry, the male nurse, put on rubber gloves and went in with a long spoon-like device and dug out the impaction. The reason for the severe constipation was the tremendous doses of Baclofin, Valium and Tylenol that HA was taking each day. HA ate more fruit and bran muffins after the painful experience of his impaction and the rest of us didn’t want the joy of the same experience so it was double fruit for desserts from then on and extra bran muffins for everyone.

My anniversary was on November 20th and I was going home for that weekend. It would be our 15th wedding anniversary and I thought I would do something special for
my wife. I phoned up the Handi-bus and got a card and the next weekend made arrangements for them to come and get me. I was excited and frightened at the same time because it would be the first time I would be out of the hospital by myself. The Handi-bus picked me up and dropped me off at Market Mall. I asked him to pick me up at five. He pushed me through the doors and then he was gone. There I was sitting in Woodwards and I could barely move my chair, but I was free and on my own. I felt euphoric. I wheeled through Woodwards and into the mall and started to shop. I was having a great time. I stopped and had a hot dog and an Orange Julius. It was difficult to eat the hot dog and drink the Orange Julius because I had to pick them up with two hands and my balance wasn’t very good in my chair. It was the first time I had actually bought anything outside the hospital. My spirits were rising and my confidence increased simply because I could buy and eat a hot dog on my own. Finally, I felt like I was living. I was feeling alive. Even though I could only move at a leisurely pace, I was propelling myself and I didn’t have to rely on anyone else or worry about a motor breaking down.

As the day unfolded, I started to wheel faster and stronger. I felt a tremendous sense of freedom and I was having a good time gliding around as fast, or faster than most able-bodied people (ABP) were. The crowd acted as a real incentive to keep even with them. I also had to learn to stop and turn quickly because of what I call the deer in the headlight syndrome. When I was wheeling in the mall that day, I noticed that if a person was walking perpendicular to the direction I was going and if I went just behind him or her, there was usually a little hole or pocket in the crowd. If I watched the flow of traffic carefully and I adjusted my speed and manoeuvred my chair well, I could cut through a crowd by going just behind people. When a person saw me coming towards them, they
would panic. They would stop and step back into the spot I was aiming for. I was so surprised the first time that I actually hit the person. Another lesson I learned the hard way was that when I passed people carrying large bags, if they turned the bags hit my chair or, in the case of shoulder bags, they hit me in the face. I learned more about handling my chair in my four hours in the mall than in the previous four months in the hospital.

When I was looking in People’s Credit Jewellers I saw her gift. It was a beautiful ring. It had one band of sapphires around the middle and on each side of this band was a smaller band of diamonds. My wife was a Virgo and the sapphires were her birthstone. The ring was fourteen-carat gold and was on sale at half price for four hundred dollars. I bought it on the spot but said I might have to bring it back and get a refund if for some reason my wife didn’t like it. I had them put it in a velvet-lined box and had it gift wrapped in the finest paper with a big bow on it. I was so proud of myself. I also bought a nice card in Woodwards. When I was waiting for the Handi-bus to come and get me I sat in the food court and watched all the people and sipped a coke. A woman walked by with a young boy that was about four years old. They got about ten feet by me and the little boy ran back and asked me, “What happened to you? How come you can’t walk?” I said, “I had an accident and hurt my neck.” He started to ask me another question and his mother grabbed him by his hand and jerked him away from me and said, in a very angry voice, “Leave that man alone.” It was as if I had a contagious disease that the boy could catch or I was a child molester. I said, as they rushed away, “It’s OK he’s not bothering me at all. I don’t mind.” I was amazed at the reaction the mother had of her son talking to me. A little while later a little toddler, about a year and a half, had escaped from her
mother. She walked up to me and started to check out my chair. She was extremely curious and started to bite my rubberised push rims. I gently put my hands under her arms and moved her back and said, in a voice I reserve for babies and little ones, “You can’t bite that because it’s not clean.” She tried to bite the rims again and I gently stopped her and said, “No, No, No. That’s not clean.” She took a wide circle and came around the front and tried to climb on my lap. I told her she couldn’t. But I knew she wanted a ride. Suddenly the mother appeared out of nowhere, like a mother bear, and grabbed her daughter and scolded her and apologised for her daughter bothering me. I said, “Your daughter isn’t bothering me at all. I have a little three-year-old of my own. She was just curious.” The woman stormed off as if she had just rescued her daughter from a life-threatening situation. Whenever I entered a store or a restaurant everyone would stop and look at me. It seemed whenever I looked at anyone they were looking at me. People would move out of my way even though they didn’t need to move. The Handi-bus was over 45 minutes late and I was exhausted from all the wheeling and the pressure of being in public for the first time. It felt like I was in the spotlight and on centre stage the entire time I was in the mall. I found it tiresome after five hours. When I got back to the General, I went straight to bed to rest and ate my cold supper. I felt happy and proud of my first outing and I could hardly wait to give my wife her present.

I was excited when I got home Friday evening. I went into the bedroom to unpack my things and hid the ring and a nice card under her pillow. We had dinner and played board games with the children. I got ready for bed first and was lying in bed waiting for her to discover her present. My wife got into bed and accidentally found her present. I said, “Happy anniversary.” she had a look of bewilderment on her face. She said, in a
confused voice, “I didn’t get you anything.” She had forgotten that it was our anniversary. This didn’t bother me because I was so excited about my gift for her. She opened the box and her eyes just about popped out of her head and she was speechless for a minute. She took the ring out and looked at it and a tear came to the corner of her eye. I said, “It’s our 15th wedding anniversary and I wanted to get you something special.” She looked at me with a sad and confused look and said; “Oh, Clark it’s so beautiful. I can’t accept this I feel so guilty.” Then she stopped and our eyes met. She continued, “I mean this is too expensive. We can’t afford this. You’ll have to take it back.” I tried to convince her that we could easily afford the ring but I had to back down because she wouldn’t put the ring on and she wasn’t going to accept it. She kept insisting that we could not afford it. I kept thinking, “We clear over 3500 dollars a month after taxes; this is the only thing we have on our Visa card; We only owe 23,000 on our house; and our total payments on our house, taxes, two vehicles, and a motorcycle were just over 600 dollars a month. We could easily afford the ring.” She just didn’t want it and the word “GUILTY” kept entering my every thought. “Guilty about what?” We argued about this for about fifteen minutes and I realised she wasn’t going to accept the ring. I also knew it was not about money. It was about something else. I was convinced it was about me being disabled, but I was afraid it went much deeper than this. I agreed to take the ring back, rolled over, didn’t try to kiss her goodnight, and quietly cried into my pillow. I believed at that moment that I had to walk if I had any hope of keeping my marriage intact.

My ability to walk slowly improved during October and November until I could, with the aide of my forearm crutches, stand by myself, walk 20 meters without a spotter,
turn, walk back to my wheelchair, turn, and sit down. No one except the people in physio knew I could stand-up on my own and walk. I decided to show off my walking ability to my wife and friends when I went home in the second week in December. I was sitting in the kitchen in my wheelchair and I asked my oldest son to hand me my crutches that I had brought with me. My next-door neighbour and his wife were over for dinner with their children so I had a large audience. I flipped the footrests to the side gripped my crutches and stood up. I thought my wife was going to faint. I walked slowly, dragging my right foot, into the dining room, turned around, and walked back to my chair and sat down. My neighbours and our children were excited but my wife acted strangely. It was a look that said, “Oh my God, he’s going to get better and come home.” I thought that being able to walk and getting stronger would make a difference in our relationship but I realised at that moment that it went beyond my disability. After we had dinner, both families sat in the living room and we watched a rented movie and ate popcorn and treats. When my friends left and we were saying good-bye I caught a split second of eye contact and body language between my friend and my wife when they thought no one was watching. I knew at that instance that they were involved. I knew that they were seeing each other. I didn’t want to believe it but I knew it was true. My marriage was in trouble. That night we made love. I felt desperate, like it was my last chance to prove myself. For whatever reason, we had a very passionate night of lovemaking. This only compounded my denial and confused me about what was going on and I thought I still had a chance to make things work. I went back to the General with renewed determination and hope and actually stepped up my exercising and riding the stationary bicycle.
I came back home on December 21st on an 11-day pass so I could spend Christmas and New Year’s with my family. I got up with the family and had breakfast but I waited until everyone left for work and school before I had my shower and got dressed in my day clothes. It was wonderful being home, in my home, alone. When I built our house I installed an extra large water heater. My wife kept it turned up to the maximum because she always liked to take long, hot baths. I liked my showers warm but I liked a lot of water falling on me in the shower. Since I didn’t use a full measure of hot water, I could sit on my shower chair and have very long showers. It was wonderful not being rushed and being alone. I showered, dressed, did the dishes and then put away all the shoes, toys and scatter rugs. I made myself a nice lunch and then a friend of mine named Earl came and picked me up and I went to the hospital and did my physio. I worked out for two hours and then Earl picked me up and brought me home at 3:30, in time to meet the children when they got home from school. The next day was going to be the same as the day before. I was enjoying a nice long shower and I bent forward to turn off the taps, just like I did the day before. I turned off the cold with my right hand, which is my weak hand, but as I turned the hot water off, the tap came off in my left hand. Suddenly there was nothing but boiling hot water streaming on my head. My first reaction was to jerk back and lean my chair against the wall. I had full sensation from the chest up but only partial sensation in my legs. I tried to lean forward with the tap and turn off the hot water but it scalded my head and I had to lean back. The water was hitting from mid-thigh on both legs down to my feet. My legs were already bright red and starting to spasm uncontrollably. I realised I had to get out of there or else I could end up dying because of the scalding hot water. I ripped open the plastic shower curtain and
immediately water spewed all over the bathroom and my wheelchair. The tub was slippery so I couldn’t get a grip to transfer. I put my hand on the middle of the seat of my wheelchair and tried to transfer. The chair was wet and lubricated and the floor was wet so the chair folded and then collapsed onto the floor. I fell onto my knees into the tub. I knew if my head and arm went into the tub I was in trouble. I gripped the edge of the tub with my elbows and stayed upright in a praying position. The water was now beating on my back and my buttocks. I had full sensation in my shoulders. I panicked. I started thrashing and grabbing the toilet bowl, the shower-chair, the tub and the walls. My wheelchair was on the floor and in the way. The shower-chair was tipped over. All of a sudden I realised I had to relax. I took two deep breaths as the scalding water seared my back and, using my elbows, pulled straight ahead and hurled myself onto my wheelchair. The force of me falling on my wheelchair pushed it to one side and this flipped me onto my back on the floor. My knees were draped over the tub and my feet were still in the tub. I struggled to get my feet out but my legs were spasming and the water was too hot to reach up and grab my knees. I tried unsuccessfully to crawl using my elbows, or turn over, but the floor and the toilet bowl were too wet to grip. I lay there with my legs burning, jumping and jerking uncontrollably. The pain was getting worse and worse but nowhere near the intensity of my bladder infection. I knew that I was only getting scalded from my knees down. Finally, after what seemed like forever, the water started running cold. In the wintertime the water in Cardston gets very cold because it comes out of a mountain stream. Being a Physical Education instructor and having a Bronze Medallion, I knew the best thing for my burns was cold water. I lay there and tried to figure out what I would do next. I thought, “I will put my chair up and climb in my chair and wheel into
the kitchen and phone an ambulance.” The chair was against the wall and it had me wedged against the toilet bowl. Everything was wet and slippery and I didn’t have the strength or ability to stand the chair up and unfold it. I had visions of being there when the kids came home. I was starting to ache and blister from the burns. I braced myself with my left elbow against the toilet bowl, reached up with my right hand and, using the back of my hand, gripping with my knuckles, grabbed behind my right knee. I took a deep breath and on the count of three, I rocked forward and grabbed behind my left knee from under my right knee using the knuckles of my right hand. I pulled with all my strength and rolled on my right shoulder and my legs popped out of the tub. I rolled onto my stomach because my back hurt so badly from the burns. I left flesh on the knobs of the bathroom vanity when I rolled over and onto the floor. I lay there for several minutes and gathered my strength. My knees had third degree burns on them. I dragged myself out of the bathroom, using only my elbows and crawling on my stomach, down the hall through the living room and into the kitchen. I left a trail of dead skin and blood. I pulled the phone off the counter and it landed on my head. I phoned the operator and got her to connect me to the hospital. I knew the person who answered the phone. I said, in a very calm voice, “I had an accident and I am severely burned. I am laying on my kitchen floor and I am in shock.” He said, “The guys just went for coffee. We’ll be over in twenty minutes.” I went ballistic. I swore violently and told him that I was barely conscious, and I was having a difficult time keeping it together and if he wasn’t there in three minutes, I’d have him fired and personally beat the shit out of him. They were there in three minutes. When they got there, I was laying on the linoleum floor shivering and spasming. My lips, hands and feet were blue and there was a slimy mass of blood under my legs.
They wrapped me in a blanket and, to my amazement, they got my wheelchair, put me in my chair, then loaded me into the ambulance. I couldn't believe it; they made me ride in my chair to the hospital. They held on to me and I rolled around. If I would have been able-bodied, they would have loaded me onto a stretcher and put me in the ambulance. As soon as I got to the hospital, they put me onto a stretcher. They simply panicked when they saw I was disabled and for some reason, they thought they had to bring my chair with me in it. I think that the worst way of dying would be to slowly burn to death. Even with limited sensation my legs ached. My right leg had been partially shielded by my left leg and was not damaged as severely but my left leg had third degree burns from mid-thigh to my toes. They put a little tent over my legs, changed the bandages every day, and put a special ointment on them. They said I would need skin grafts for both legs. I prayed they would heal.

I spent Christmas in the hospital unable to move. On Christmas Eve my wife and children came to visit me and they brought their presents for me and opened my presents for them. We've always had a tradition of opening one present on Christmas Eve. We opened our presents and had a good visit. My wife seemed even more distant than usual. It was as if my accident pointed out how disabled I was. She seemed icy cold and distant. I had a good time in the hospital because I knew I was going to heal and that no permanent damage was done. I might have scars but I thought that my legs didn't work that well any way. It also gave all my friends an opportunity to visit me. My good friend Nick came all the way from Calgary to see me. I healed rapidly. After one week the nurses told me I wouldn't need a skin graft. It was three days before New Year's and we had planned to go into Lethbridge for a dinner and dance. I was determined to go.
While I was in the hospital, my wife came to see me each night for a short visit. She treated me more like a brother or an uncle rather than her husband and lover. On the last Friday before New Year’s, she said she would not be in tomorrow because she was going to go shopping in Lethbridge with her girlfriend. Each day she stayed a shorter period of time and it seemed like she was simply going through the motions. We didn’t seem to have anything to talk about. Each time she would kiss me good-bye on the lips. It felt strange. I couldn’t put my finger on it. Then, that Saturday, when she was shopping, my neighbour from three doors down, visited me. She was 35 and had seven children but was still the best female athlete in the town. She liked to play badminton against me because I could beat her and it made her better against female competition. She was an attractive and energetic woman and she liked and respected me. She brought me some treats she had baked and visited with me for over an hour. When she was about ready to leave, she gave me a big hug and kissed me on the lips. It was like a mother kissing her son good-bye. It was moist, and warm, and full of love. My wife’s kisses were cold and dry. I knew her love for me had gone.

On New Year’s Eve I got bandaged up, put on my suit, and took some Tylenol number threes. My friend, his wife, and my wife picked me up and we went into Lethbridge to the Park Plaza and attended their annual New Year’s Eve party. We had a nice dinner and then there was dancing. I had a good time but I was in a lot of pain and I noticed my wife and my friend talking a lot. When they danced, I could tell by the look in their eyes and their body language that they were involved.

I went home that night. Each day for a week I went to the hospital to have the bandages changed and I started physiotherapy again. When I started physio again, I
couldn't believe how much strength I had lost in just ten days. I worked out all that week at the Cardston Hospital and it was decided that I should return to the General on the next Monday. All that week I was home alone and my friend Earl took me to the hospital and picked me up and took me home after physio each day. On Saturday night, January 6th, we were laying in bed talking and I put my arm around my wife and tried to snuggle closer. She moved my arm and pushed me away and said, "Clark, I want a separation." I was surprised. I said, "What do you mean? We are already separated. I am living in the hospital in Calgary." We had an argument and we decided that I would go back to Calgary and come home in two weeks and we would talk about it.

That first week back at the General was difficult. If I wouldn't have been burned, I am certain that I would have been released early in January. I tried hard in physio and by the end of the week, I had nearly recovered my strength to the level I had before the burns. On January 12th just after supper the nurses said I had a call at the nurse station. I was excited because I knew it was my wife. My joy was short lived and my life was to change dramatically again. She said that she wanted a permanent separation and that she did not want me to come home. She said she did not want me to come home ever again and that our marriage was over. I was devastated. I started to cry and I couldn't stop. I didn't want anyone to see me so I went upstairs to the eighth floor and sat and wept.

What was I going to do? Where would I live? What about my children? How would I take care of myself? Would I ever be with my wife again? Would anyone else ever love this 37 year-old cripple? These thoughts would race through my head and then I would cry and cry. This seemed like the last straw. I had worked so hard and tried with every fibre of my body but this seemed to overwhelm me and take all the fight out of me. I
cried for a long time and then wiped my eyes and phoned some of my friends in Cardston and told them that my wife had asked for a separation and that she was having an affair with my friend. They all told me that she was not having an affair but that she simply couldn’t adjust to my disability. My friend PC was the only one who had noticed something but didn’t want to say anything in case it was his imagination. He said he would keep an eye on things for me and let me know what was going on. It was Saturday night and everyone was watching TV. I wheeled in and was barely under control holding back the tears. Everyone looked at me and TB asked me what was wrong. I burst into tears and told him, through the sobs, that my wife had just asked for a permanent separation. He wheeled closer and put his arm around me and put my head on his shoulder and just held me and I wept and said, “What am I going to do,” over and over. The others quietly left and TB held me. In a few minutes I calmed down a little but I asked him again, “What am I going to do?” I sat up and wiped the tears from my eyes. I was a little embarrassed. TB sat with his arm around me and had a kind and concerned look on his face that made me know that it was alright to cry and act so weak. He told me about how he broke up with his wife. He had been in the hospital for seven months after his accident but had to return seven months later because of pressure sores. When he went home, his wife wasn’t there. She had moved out and taken the children with her. TB told me that at the time he was just mad at the world and that his head injury complicated everything. He said a lot of it was his fault because he was so angry about losing his body. He told me that losing his body was worse than losing his wife because it is easier to replace your wife. He also explained that the two losses didn’t simply add on to each other but were more than twice as hard to deal with than either of the losses would have
been alone. They had a multiplier effect like a geometric progression. His story calmed me down because I realised that this happened to quads all the time. I asked him, “What am I going to do now?” TB told me that you simply survive. He said you have to forget about the past because it is gone and there is nothing you can do about it. You can’t worry about the future because it does not exist. You have to live in the moment, in the here-and-now. He said to set small goals and focus on what you are doing. He said that when you wake up in the morning just make it to breakfast; then concentrate on making it to coffee break; then lunch; then coffee; then supper; then sandwich time; then bedtime; then till you fall asleep. He said to concentrate on whom you were talking to, or whatever you were doing and to try and enjoy it. To “lose myself in the moment” was the most valuable advice anyone has given me on survival and maintaining sanity in a desperate situation. We talked for about an hour and a half and no one, staff or patients came in to disturb us. Then FF, HA, and TT came into the room and asked me if I was OK. We ordered some pizza and Barry brought in a movie for us to watch. I was feeling better but I was so sad. That whole week I would cry softly into my pillow each night for hours. I tried to work out hard but my heart wasn’t into my workouts. I was feeling so sad. I phoned my friends and talked to them each night till they were sick of hearing me call. A close high school friend of mine, BD and his wife KD, helped me out at this time. She would come and pick me up and let me talk to her and I would cry. I don’t know what happened to me because I never cried before my accident. I am much more emotional now than before and I was more likely to cry or be sad than get angry and lose my temper. Perhaps it is because I couldn’t strike out or do anything physical like fight, or run, or rip things up, so the only release was to cry. When I hear a story about the death
of a child, a plane crash, or a crippling accident, my heart is saddened and I have a feeling of empathy for the parents, family and friends of those who have been hurt. Later that week I was in bed and I had been sobbing and crying for about two hours and I thought I heard something. I stopped crying and I could hear quiet sobbing from one of the beds across from me. I lay there in the dark and listened to this other young man quietly cry. I felt so much empathy for him. It seemed to take away all my pain but made me feel more sadness than I had felt before because he had lost everything at 18. There was no going back. There was no escape. His body was gone; his relationship destroyed. Life as he knew it was over. The finality of that swept over me in the dark hospital room on a cold, bleak winter’s night as I lay there and listened to a young man with a broken heart and broken dreams weep. It overwhelmed me. Because all you can do about it is try to make it to coffee. There is nothing else. Hope seems to disappear and depression constantly raised its ugly head. I then realised that I couldn’t lose it, because it would have a negative effect on some of the fresh breaks that looked up to me because of how hard I worked out and how long I had been there. I decided to act as if I had a positive attitude. I became determined that I was going to walk. Get a better job. Make lots of money and drive down to Cardston some day in a Porsche and have a beautiful woman with me. I would do it all. I’ll show her! I didn’t cry at night any more after that and I started to work hard again. I used my anger to fuel my recovery but in my heart I was still in love and I missed my wife and family. My next goal was to be able to transfer from the floor to my chair. This would mean that I could live completely independently because I wouldn’t need anyone around in case I fell out of my chair in the real world. On the outside I was all smiles and good humour, flirting with the nurses and therapist and being
kind to the fresh breaks, but on the inside I was sad, disheartened and missing my wife and my children. It was useless to cry and talk about it because the situation was out of my control. This feeling of impotence, of not being able to control my environment was difficult for a formerly competent person who was used to succeeding at everything he did, to accept. In sports, if you had the skill, worked hard enough, and had a good plan, you would be successful and probably win a championship. In rehab there seemed to be no justice. Return was not a reflection of effort or planning. JC, once said, that the body seemed to have its own timetable of healing. I was one of the lucky ones. For some reason the good Lord allowed my body the ability to get a little return and this was enough to keep my hopes alive that someday I would get more. I worked out harder than before. I worked on the stationary bike and the leg machine for 15 minutes each day and spent an hour on the mats trying to get into my chair from the ground with no help. This was in addition to my weights and stretching. I was getting into tremendous shape for any one, never mind being a quad. I found that if I focused on my workouts, I didn’t have to think about anything else. It gave me a feeling of pride at the end of the day to know that I had worked so hard. I started to walk stairs with my crutches. I could go up without a problem but going down was impossible at first because I didn’t have the strength in my legs. By the end of January, I could transfer into my chair from the ground. I was proud of this because I had invented a new way of doing it based on my specific abilities. I was also walking up and down stairs and could walk one whole lap of the eighth floor without a spotter.

During the second week of January, because I was so independent, I was moved from room 4 to room 6, which is at the furthest point from the nurses’ station. Lorraine
came and talked to me and said that she would like me to be roommates with a new patient who was coming over from the Foothills. He was a young man who had broken his neck at C-3, C-4 in a rugby accident. This meant that if he didn’t get any return, that he would need an electric chair and would have limited function of his arms, no use of his hands, and may need assistance breathing. Basically he would do everything by blowing into a straw. I told Lorraine that I would like to help. This gave me something else to do and think about besides my own problems. In fact, this acted as a reality check as to exactly how lucky I really was. RP was a nice young man and was still in shock and disbelief that this was happening. He had a loving family and a beautiful girlfriend. His parents came every night and his girlfriend and school friends came often during the next three weeks. Soon, however, only his family was coming on a regular basis. My wife had quit coming to see me but her parents came at least once a week and my mom and dad came to see me three times a week without fail. My friends from Cardston only came once every five or six weeks. Slowly I could feel the support that had sustained me drift away. At first I had visitors every night for two or three hours. Now I would usually have my parents for a half an hour three times a week. HA had moved home with his parents but his relationship with his girlfriend ended because of fights they had about living with his parents. FF was having trouble with his relationship with his girlfriend and I could tell it was doomed. JC was still able to maintain his relationship with his wife. In fact, it seemed to work as a catalyst with them and made them determined that they were going to beat this thing. There were about thirty SCI males that I got to know on the floor and JC was the only one who managed to sustain his relationship from before his accident. Our wives and girlfriends left the rest of us while we were in the hospital or within three
months of our release. The reasons were all different, it seems, but any problem that existed before the accident was magnified way out of proportion and usually one person or the other was unable to accept the reality of life as a person with a SCI. I observed that, in most of the cases, it was the frustration of the man with the SCI because he was unable to cope and adjust to his new body and the reality of the change. In these instances it appeared that the women were willing to make any adjustment or sacrifice within reason to make the relationship work but the men were unable to accept their new bodies. I believe it is difficult for a man with a SCI, when he is first injured, to honestly believe that a woman would love him and want to be with him when he cannot move, make love or support her financially. Sometimes the men feel that they don’t want to make a woman live with them when they can’t contribute their fair share to the relationship. Love can be strong enough to sustain any tragedy. I know, in my case, even though I didn’t want it to happen, I could understand my wife wanting to have a partner who could perform sexually and physically do the work around the house that needs to be done. When I would reverse the situation, I would always wonder, “Would my love be strong enough to stay true and not seek another sexual partner or someone to take care of all my other needs? Would I be content being a long-term caregiver and sacrificing my free time and hobbies? I would also think that if I really loved someone would I want her to spend her life looking after me?”

At that time I didn’t feel worthy of having a beautiful woman love me and this was punctuated quite loud and clear when my wife asked for a separation. This was also conveyed to me by the fact that everyone stopped visiting me as soon as I started getting stronger. When I was first injured I had a difficult time with my self-image. I couldn’t
figure out who I was. Every one said, “Just be yourself.” I kept wondering who that was because so much of who I was, was wrapped up in my job, in my ability to play sports, in my coaching, and in my marriage. All those things had disappeared and I didn’t know what was left. Be myself. What was I now? A crippled 37-year-old man, without a job, wife, or a place to live. Is that who I was? I certainly wasn’t a vibrant, successful, athletic teacher and coach. I didn’t have a beautiful wife and family I lived with. I didn’t live in a nice house. I couldn’t play sports or go hunting or fishing. Just be myself. It was a joke; only I didn’t find it at all humorous. My sense of identity was stripped away. My identity had been completely tied up with the physical expression of who I was.

I observed that most of the young men who get SCI derive much of their self-identity from their ability to perform athletically. In many instances this desire to push the envelope of accomplishment a little farther is what ultimately leads them to their accident. Perhaps there is a sense of guilt about having caused their own catastrophe and the loss of identity that causes such grief. If only I had gone a little slower, or more under control, or more to the left. Or even, I should have stayed home that day. The “would’ve, should’ve, could’ve” syndrome can drive a person insane. I watched CE go through this his first month. I tried to help but what can you say to a young man when the girl he loves just wants to be friends all of a sudden. How do you comfort someone when you are getting a lot of return and he has to breathe with a tracheotomy? All you can do is listen to him cry quietly into his pillow late at night when he thinks everyone is asleep and never mention that you heard him crying for three hours the night before. Hang out with him at night, run the ramps, watch movies and eat pizza. Let him talk about the past, about his girlfriend and Rugby. It really doesn’t matter. Simply give him your time and
an empathetic ear. I know that by helping CE deal with his loss, which I considered
greater than mine, I was greatly helped. I came to the conclusion that I was lucky because
I had lived a good life. I had been married for 15 years, had four great children, had won
a Canadian championship, and I had been a very successful coach and teacher. I had
experienced 16 years of adult life. He had experienced none. He wasn’t even out of High
School. He had never really been with a woman and I had been married to the woman
that I had wanted to be married to for, 15 years. I figured most men couldn’t say that. I
also went out on top at the peak of my athleticism and coaching ability. I honestly
thought that my life was basically over and that other women wouldn’t find me attractive
at all. I didn’t think I could coach and teach physical education or coach basketball in the
physical condition I was in. I kept thinking, “I have so much more return, so much more
experience, so much more education. How is he going to make it?”

We would talk about these things on the eighth floor. Some of the young breaks in
their teenage years would argue that it was better to be young and start fresh as a para or
quad than to be my age and have to give up the past and retrain and start all over. I think
a lot depends on the person and his situation. I know I wouldn’t want to give up those 16
years but it is almost impossible to give up all those years and start over with a new body
that doesn’t function as well. The advantage of youth is optimism and adaptability. Many
of them want to get on with life, whereas those of us that are older know how hard it is
even as an able-bodied man. I shudder to think about competing as a SCI person in this
modern age. We would also have discussions about what is better; to be a partial quad
that could walk a little but couldn’t use his hands very well and didn’t have full upper
body strength or a para with full upper body and use of his hands. The paras would argue
that they were more mobile and functional than partial quads and the quads would argue that they could walk stairs, had better sexual performance, didn’t have to wear leg bags, could go places the paras couldn’t go, and that walking improved our health by helping the internal organs and digestion work better. I wouldn’t want to give up the function I had as a walking quad but it would be fun to be able to participate in wheelchair basketball or work on a car’s motor again. It would also be nice to be able to wheel a chair hard like the paras can. This was an ongoing conversation but we all agreed that the worst disability would be to be brain damaged and not have our original memories and the ability to communicate with other people. Everything we talked about was focused on our injuries, our bowel routines, or our relationships.

The fact that we had a common bond through being SCI and that we were dealing with common problems and losses brought us very close together. We tended to look after each other and talking to another break was usually superior to talking to an able-bodied counsellor or psychologist. I passed the advice that TB had given me on to RP and some of the others when they wanted to know how I had managed to survive. We would sit in a room as a group and talk about everything. Discussions were usually pretty frank with roommates because there were no secrets. You could hear everything that the doctors or the spouses of each person said. I knew how many grams of what medications each of my roommates was on. I knew when their bowel routines were and when they bathed. I knew when and if they had visitors. If someone’s girlfriend didn’t come when she had promised she would, I would always be gentler with his feelings. It was in these sessions that we learned a lot about spinal cord injuries and found out how different we all were and that no two breaks were the same. Everyone healed differently and had
slightly different abilities. A perfect example of this is JC and myself. We were both C6-C7 partial lesion quadriplegics that could walk with forearm crutches; however, this is where the similarity ends. My left side had more return than my right side but JC had more return in his right side and much less than me on his left side. His abdominal and his triceps were almost normal but mine didn’t work very well. My left hand worked at about fifty percent and my thumb could pinch almost normally but my right hand hardly worked at all. Both his hands worked about the same, a little better than my right hand but not as good as my left hand. My left leg had tremendous return and my right leg didn’t have flexors that worked very well. JC’s right leg had almost as much return as my left leg but his left leg was worse than my right leg because it had a lot of spasticity. JC used to joke with me that we should flip a coin and one of us would get the strong sides and the other the weak sides. We would laugh because together we would almost make an able-bodied person.

RP was weak and his blood pressure was low when he first came into my room. He would faint each time they tried to sit him up. I told him about the difference between the white spots and the purple spots. I showed him how to breathe and flap his arms but RP couldn’t move his arms very much. He was too weak to push his manual chair and had to breathe with a tracheotomy. One morning the OT came riding into the room in a brand new electric chair. RP got really excited. They transferred him into the chair and strapped him in. RP was like a kid in a candy store for the first time. His smile on his face grew with each minute as he practiced in the room. The chair was quick and responsive and would go at least ten miles an hour. RP took the chair out in the hall and disappeared. He flashed back in two minutes later and hit a table because he was going too fast. Words
cannot describe the look of complete joy on his face. His whole attitude changed because
now he was mobile and had some measure of independence. In fact, he could go
anywhere wheelchair accessible quicker than any of us in our regular chairs. He, once
again, had a sense of pride about being able go places and do things with the rest of us.
He would wheel himself to physio, run the ramps with us, go and watch basketball
practice, and come down to the games room and watch movies with us. RP didn’t have
enough strength in his hands to eat or pick up anything. We would all sit together and eat
our pizza and watch a movie Barry would bring in. RP would simply look at me and nod
and I would hold up his piece of pizza and he would take a bite and I would put down his
pizza and watch the movie. We did this so often that he would just move a little and I
would hold up the pizza or sandwich without looking and after he took a bite put it down
without interrupting whatever I was doing or saying. I usually ended up being the one to
feed him because I was the only quad who had a hand that worked well enough to hold a
piece of pizza with one hand. It was difficult for me to watch RP work out so hard and
get no return. I admired him because he kept fighting and trying so hard. RP got so that
he didn’t need his tracheotomy and he was fortunate to get a little return in his right hand
that enabled him to have good control of his electric chair.

When I was moved from 4-D, a young man of 25 was moved into my old bed. His
name was DA. DA had been partying one night and the woman he was with gave him
some angel dust. DA got so high that he thought he could fly. He stepped off the balcony
and shattered his legs and his pelvis. At first he was in a body cast with only a little hole
in the front so that he could be catheterized. After a month the cast came off and he was
ready to start rehab. He had broken his spine at S-1. This meant that he had everything
except for his bowel, bladder and legs. DA refused to cooperate. He wouldn’t dress in the morning and refused to work out. DA felt a lot of guilt because he had been with a prostitute and his accident had been totally unnecessary. I tried to help him get going but he didn’t want to. He lay in bed all day and wouldn’t do anything. He would come with us in the evenings and wheel the ramps but he wouldn’t cooperate with the nurses at all. The Hospital shipped him to an extended care centre in mid-February because he refused to do any rehab activities. DA was extremely high functioning and had total upper body strength including stomach and back muscles, whereas RP had virtually no return below the neck. DA was higher functioning than anyone on our floor. He couldn’t walk but he had full return above his groin area. However, he had the worst attitude of anyone on the eighth floor. FF, RP or any of the people on the floor except TT, JC, or myself would have done anything to have the return he had but he didn’t appreciate it and refused to maximize his healing potential for those first few critical months.

I didn’t know what to do at this time. I didn’t want to make arrangements to move into a place of my own because I hoped that something would work out with my wife. My wife said she didn’t want counselling and seemed determined that she wanted a permanent separation. I sensed that my marriage was basically over. I went to see Dr. Blaire about my dilemma and asked him what I should do. Dr. Blaire was a brilliant man and was in charge of the entire H block and the head of psychiatry. When he retired, they hired three men to replace him. He told me I could stay in rehab as long as I was improving and until I could find a place to move to. I explained to him that I felt that if my wife left me, I wouldn’t ever be able to find another woman to love me. I felt that my life was over. I asked him what I should do. He surprised me with his answer. He said
that in his 30 years of counselling people with SCI, he had one rule that he followed and that was, “Advice is for fools.” I felt totally helpless and confused. What was I going to do? Would I ever have another relationship with a woman? Dr. Blaire was an extremely busy man yet he talked with me for over an hour. He was an avid basketball fan and both his daughters played high school basketball; one of his daughters was on the Alberta Junior Basketball team. Dr. Blaire was only two years away from retirement. We talked basketball and sports and then he said I want to tell you a story. He said that by the time he finished medical school and did his residency, then did his residency for becoming a specialist, he was 38 years old and not married. Being a scientist he decided to research what combination of ages for a man and a woman made for the best relationships. He found that Picasso, Pascal, Dali and many other prominent men had married women younger than themselves. From his research he found that men about 38 and women about 25 were a perfect match because he explained they are looking for the same things. Men at 38, he explained, were set in their careers and ready to raise a family and have a stable relationship and 25 year old women want a secure relationship and to start a family. He said that he then meet and married a 24 year old woman and has been happily married ever since and has two lovely daughters. Without giving me any advice, he had simply told me a story about his life that filled me with hope. As I wheeled back to my room, I realised that he had given me a gift of insight and I laughed because he had told me through a story that my life with women was not over and that I was at the perfect age to marry again. His hour and a half with me gave me hope that even if my marriage failed, I could find someone else. I still didn’t believe this to be true because deep within me I didn’t think that a woman that I would desire would want to be with me.
Some of the nurses on the floor were starting to say things like, “How come you are still here,” and they would always make me wait till last before they would help me. I was physically ready to move on but I was psychologically a mess. I didn’t have a place to go to and I wasn’t prepared to take the next step of total independence. I was completely unprepared for the realities of living alone in an able-bodied society.

My friend Nick was very kind to me during this period of time and would come and take me to poker games with my old high school friends and take me to Flames hockey games. One night Nick was going to pick me up for a Flames game and I was really excited. I went downstairs and waited. Suddenly, I felt something and I got that putrid smell of urine. I looked down and I had blown a condom and I had wet myself. I raced upstairs and whipped into my room. I asked the nurse to help me because it was an emergency and someone was picking me up to go to the hockey game. She said, “This is a rehab floor and you can change yourself.” One of the nurses I had made an enemy of was extracting her revenge. I went ballistic and swore at her and stripped down as fast as I could and washed at the sink. I had been wearing my best dress pants and shoes but now I lay on my bed and pulled on my pants. Just then, BA, one of my favourite nurses, came in and said, “What’s all the commotion.” I explained my dilemma as I dressed. BA threw my socks and shoes on me and helped me put on my coat. I raced back downstairs. Nick was just arriving when I got to the door. I knew I had been there too long but I felt like I had no other options.

My wife had agreed to go to counselling but I made the mistake of allowing her to pick the counsellor. I went alone and told him my story. I told him that I suspected my wife and my friend were having an affair. I told him that my wife was having a difficult
time with my injury and that we were having some difficulties since she went back to
work two years earlier. Then he had her come in by herself and he interviewed her.

I was completely unprepared for what happened at the next meeting I had with
him alone. He said, and I quote him exactly, “Clark, you fucked up.” I was devastated.
He completely discounted my story. He believed my wife when she said that she wasn’t
seeing my friend and that she needed time and space, and that I had been mentally cruel.
Mental cruelty consisted of not wanting to give up participating in sports as a player or
give up coaching high school basketball and a dream of coaching college ball. When I
left the doctor’s office, I was picked up by my friend’s wife. As she drove me back to the
hospital I told her what had happened and I cried and sobbed uncontrollably. She
couldn’t comfort me. When I got back to the hospital, I went straight to bed, closed the
curtains and I cried for a long time.

It was the middle of February and my heart was broken. It felt like something had
died inside me and my will was broken. I went to my workouts but I had trouble being
enthusiastic. I was so sad. I felt that my world had collapsed and all hope for my marriage
was gone. I was getting stronger with what I had but there had been no new return for
two months. I was restless and knew that something had to be done. I was thinking about
moving home and forcing the issue but my wife got a restraining order and a legal
separation. I was angry and knew I would have to do something but I didn’t know what. I
was wheeling in the hall that evening and Sara was sitting in front of her room, as she
always did, and as I wheeled by she asked me if she was going to be all right, as she
always did. I would usually wheel by and say, “You’ll be all right Sara.” But, for some
reason, I stopped and talked with her. I told her she was going to be fine. She had
experienced a stroke and was a complete hemiplegic. Her entire right side was paralysed. She was grateful to have company and I was surprised at how sharp her intellect still was. As we talked, I said that I wished that I was 21 again, able-bodied, and could do it over. She looked at me with her one good eye and said something to me that would stay with me for the rest of my life. She said, "I wish I was 38 again and could do it all over again." She kept looking at me and neither of us said anything for a long time. I said, "Sara, I really do think you are going to be all right." I said good-bye and continued wheeling and thinking about what she had said about not having any regrets and living life to the full. I knew then that I had to get out of the hospital and do something. I couldn't stay there forever.

When I arrived at the General, I was assigned a social worker to help with things like getting ramps, finding a place to live, getting funding, and transportation. They were also supposed to give us psychological and social support for any of the problems that we had. My social worker (GC) was a young woman in her mid-twenties who had been out of university for three years. GC was very conscientious about her job. I received my ramps and all the other things I requested. GC was an empathetic listener and tried to help me as much as she could. When my wife asked for a separation, I needed to talk with someone so I was referred to my social worker, GC. The problem was that I needed a lot of time with someone who understood my dilemma. Unfortunately, GC could provide neither. She had an extremely large caseload and could only see me for an hour once a week, twice if I was lucky. When you are in crisis and desperate, you can't wait till next Thursday; you need someone immediately. It's also difficult to put any credence or value into something a young attractive woman, who has never been married or had
children, or has never suffered a serious disability, is saying to you about how to deal with your situation. She didn’t believe that my wife was having an affair and thought I should give her time and space. I sat and listened to her and thought, “You don’t have a clue about anything that is happening to me.” Everyone thought that I had an overactive imagination or that somehow my injury had triggered a false belief system, but I knew exactly what was going on and I was frustrated and confused because it seemed I had no one to turn to and nowhere to go. My wife and my ex-best friend have now been married for 13 years. The only person who believed me, at the time, and also could see what was going on was my friend PC.

The next Wednesday my friend RM came to visit me on his way home from northern Alberta. He was one of my neighbours and a good friend. As we visited, I suddenly got a plan. I asked him if he could give me a ride down to Cardston. He said that he wouldn’t mind giving me a ride and that his three quarter ton truck was just about empty. I asked him if he wouldn’t mind waiting while I made a phone call. I called my friend PC and asked him if I could stay at his place for a while. PC has seven children and lives in a large eight-bedroom home. He built a full sized racquetball court on one end of his house and there was a large fold out couch in the mezzanine of the racquetball court. PC was happy to hear from me and told me and said I could come and stay with them for as long as I wanted to, as long as I didn’t mind staying on the mezzanine. I went back to the room and MR helped me load all my clothes, personal belongings and my wheel chair onto the bottom of a stretcher bed. We put a sheet over it so that no one could see all my things. We cleaned out my room. I went to the south side of the nurses’ station and got an extended weekend pass. While I had the nurses diverted, MR moved the
stretcher bed past the station on the north side and took it down to the truck. I checked out and then walked into the room where Klause, the male nurse, was working with one of the new patients. I said, “You see Klause I am walking out of this hospital.” He gave me a strange look and I walked to the elevator. I went down the elevator and walked to the truck. It was the longest walk I had yet attempted but I knew I had to walk out of there. MR had already loaded my wheelchair and my clothes into the truck. When I walked out he helped me into the truck and put my crutches in the back. As we drove away, I didn’t know what was going to happen but I knew I had to do something and that it was time to leave.

Personal Motivation for Research

When I left the hospital, I was angry at the way that I had been treated. My body had been taken care of but I felt that my psychological concerns had not been adequately addressed. I thought that the reason for this was that the healthcare workers and doctors didn’t understand the experience of the trauma of SCI. I thought that before someone could possibly counsel someone or do psychological interventions, it would be necessary for him or her to understand what factors were involved and how they interact to shape the experience of a person with a SCI. All that the professionals had to rely on was clinical observations and research. Clinical observations are dangerous because able-bodied people are, as Bollnow (1974) states, “outsiders.” Many times these observations are not accurate interpretations of what the person with a SCI is really experiencing. There has been a tremendous amount of research done on SCI; however, many of the results are conflicting (Craig, Hancock, Dickson, Martin, & Chang, 1990). When I was released from the hospital, I was unhappy about the way I had been treated in
rehabilitation by psychologists and other professionals. I was also intrigued by a statement made by Jubala and Brenes (1988) when they said, “Despite intensive research, such is still speculation for we do not have even a basic understanding of what it is the spinal cord injured individual really undergoes.” I thought that only a person who had actually experienced a SCI could possibly explain the experience. I decided that I wanted to help others better understand all the factors that contributed to the experience of the trauma of SCI and how they interacted and influenced a person with a SCI. I believed that this experience could only be understood and explained by qualitative research because of the complexity and sensitivity of the topic. There seemed to be too many variables and it appeared that the only possible way to “get at” the experience of the trauma of SCI was to interview people who had experienced SCI. Then, using the interviews, the literature on SCI, and my personal experience of SCI, do a phenomenological-hermeneutic interpretation of the data and develop a model or grounded theory to explain this phenomenon.

Statement of Purpose

The purpose of this study was to explore and understand what happens psychologically to a person who experiences the trauma of a SCI. Specifically the following areas were addressed.

1. A review of the research literature on SCI was conducted to help understand the experience of the trauma of SCI and ultimately the adjustment to SCI.

2. Men with SCI were interviewed to understand their experience of the trauma of SCI and their adjustment to SCI.
3. The similarities and differences between the lived experiences of the
   participants and results of research on SCI were examined.

4. The possible implications this study may have for the rehabilitation and
counselling of people with SCI were explored.

5. The implications for further research were considered.
CHAPTER TWO

LITERATURE REVIEW

The literature review represents an important and integral part of this dissertation. The topics selected in the literature review evolved as themes emerged from the transcripts of the interviews and as I attempted to “make sense” of the data. There was a constant dialogue and interaction between the literature, the data, and myself. There seemed to be a snowball effect in the readings because each article seemed to link to a new topic and more articles. As I read more articles, expanding my knowledge base, the understanding and the interpretation of the data and the themes seemed to shift over time. This continued for six years until I reached a point where suddenly everything fit and seemed to make sense. I realised that, because of the complexity of the topic, I needed to present a thorough summary of the literature. Following is a review of the literature to help understand the topic, “Understanding the trauma of SCI.”

According to the Canadian Paraplegic Association (1999) there are approximately 35,000 people with SCI in Canada. The incidence rate of SCI is virtually constant at 1600 per year or 5.7 per 100,000, half of them experiencing quadriplegia; the other half paraplegia. Males comprise 80% of the SCI population and 80% of the population was injured between the ages of 19 and 34. In the province of Alberta the incidence rate is slightly higher at 6.7 per 100,000, which equates to approximately 200 SCI per year. The general statistics for the United States appear to be quite similar. The average age for a person with a SCI has been reported to be 29 years with a median age of 25 and a modal age of 19. Males comprised 82% of all people in the U.S.A. with SCI and there was an
equal distribution between people with quadriplegia and paraplegia (Stover & Fine, 1986).

Trieschmann (1988) stated that rehabilitation is a process of teaching people to live with their disability in their own environment. She developed a theory that stated that the behaviour of a person with SCI \([ B \] is determined by the interaction of the psychosocial (P), organic/biological (O), and environmental (E) factors; simply written, \([ B=(f)P,O,E \]. Trieschmann (1988) maintained that a SCI causes disequilibrium in the psychosocial, organic-biological, and environmental aspects of a person’s life. Health and adjustment can only be achieved if a balance can be re-established. This means that the person with a SCI must deal with more than the physical or organic-biological problems before he or she can re-establish homeostasis. The psychological, environmental, and spiritual aspects of one’s life also have a critical influence on the health and adjustment of a person with a SCI. In the past, the concentration in rehabilitation has been on the medical model. The emphasis was on helping the person with a SCI heal the bones and tissues, regain his or her strength, and become as high functioning as possible. However, little time was spent on a person with SCI’s psychological or social rehabilitation (Trieschmann, 1989).

**Organic Factors Involved In SCI**

There are few things that have a greater impact on a person’s life than a SCI. From the moment of the accident, the person with a SCI experiences the following:

- Loss of movement below the level of the injury
- Loss of the sensation of touch and pressure below the level of the injury
- Loss of the sensation of pain below the level of injury
- Loss of immune system function
- Loss of sexual function
- Loss of ability to digest food
• Loss of ability to breathe normally
• Loss of sensation of smell because of mucus in the nose

When a person first experiences a SCI, there are, in many cases, other physical complications. With neck injuries there are often complications with closed head injuries. With injuries to the lower spine, often there are internal injuries. There is also the possibility of damage such as broken legs, hernias, torn ligaments, muscles and damage to other soft tissues. The problem is that many of these secondary complications can go undetected initially. The body, at this time, is struggling to survive and is in shock. Spinal shock can last for as long as three months. Until the swelling subsides and the spinal shock is over, it is impossible to determine the complete amount of the damage the spinal cord received or the extent to which the person will be able to recover function and use of his or her body. This is further complicated by the improved methods of care during the first few hours of injury and the use of powerful anti-inflammatory medications that prevent swelling and further damage to the spinal cord. This improved care in the first few hours translates into an increase in the number of people with SCI who have partial lesions and an increased return of function. When a person experiences a SCI, there are direct medical complications that may occur in the following systems of the body (Sridharan 1992, pp. 1-11):

1. Cardiovascular
   • Pulmonary edema
   • Acute hypotension and bradychardia
   • Deep venous thrombosis
   • Pulmonary emboli
   • Orthostatic hypotension
2. Respiratory
   • Respiratory failure
   • Impairment to effectively cough
   • Pneumonia
3. Gastrointestinal
   - Paralytic ileus
   - Chronic neurogenic bowel
4. Genitourinary
   - Neurogenic bladder
   - Urinary tract infection
   - Bladder sphincter dyssynergia
   - Autonomic dysreflexia
   - Sexual dysfunction
5. Musculoskeletal
   - Heterotopic ossification
   - Osteoporosis
   - Spinal deformity
   - Spasms
   - Shoulder problems
6. Neuropsychological
   - Chronic pain
   - Syringomyelia
7. Skin and Integument Structures
   - Dicubitus ulcer (pressure sores)

The Effects Of Stress

SCI accelerates and complicates the normal process of ageing (Trieschmann, 1987). This is a product of continuous stress on the person with a SCI. The stress comes from constantly attempting to normalise a situation that is constantly being thrown into disequilibrium by factors directly related to the SCI and by other factors and life situations that naturally occur. For example, people with SCI are more likely to be frequently hospitalised for extended periods of time because of dicubitus ulcers (pressure sores), bladder infections, pneumonia, and renal failure (Trieschmann, 1987). This often creates problems because individuals are unable to keep full time jobs, which creates a situation where there is a problem with sufficient funding.

There appears to be no sure method of predicting who will become spinal cord injured or who will successfully adjust to a SCI. There appears to be no correlation between level or completeness of break and the degree of disability and adjustment or
personality reaction to SCI (Brenes, Dearwater, Shapera, LaPorte, & Collins 1986; Cook 1979; Shontz, 1984; Thompson & Dexter, 1980). Kennedy, Gorsuch, and Marsh, (1995) confirmed these studies and added that it did not matter if a person was involved in a significant relationship or not, there did not appear to be any organic variables that were predictive of long-term psychological adjustment.

There is evidence that peoples' ability to cope prior to the accident is predictive of their ability to cope and adjust after a SCI (Bracken, Shepard, & Webb, 1981; Katz, Gordon, Iverson & Meyer, 1978; Young, Burns, Bowen, & McCutchen, 1982). Jubala and Brenes (1988) identified the following personality traits as being predictive of being able to cope well with the trauma of SCI:

- Being young and having a positive family experience
- Positive personal, inter-personal support
- Financial security
- Strong sense of independence
- Aggressiveness
- Creativity
- High number of plans for the future
- Good education and theoretical interests

Dinardo (1971) found that people who exhibited an internal locus of control were likely to spend less time in the hospital and they displayed a desire to learn about SCI. McCann and Pearlman (1990) established that a strong personal identity was helpful for individuals experiencing SCI in maintaining their identity, personal boundaries, and affect regulation or control of their emotions. Erickson (1982) stated that people who possessed a mature ego could operate from a solid base when they were put under stress.

A SCI is one of the most stressful events that can happen in a person’s life. The pre-morbid coping skills are highly predictive of the person’s capacity to cope with this new event. However, if individuals’ capacity to cope with the stress of their SCI is
exceeded, it may trigger a cascade of organic changes in their bodies (Drevets & Raichle, 1998; Drevets, 1999; Duman, 1998; Duman, Malberg, & Thome, 1999). Hohmann (1966) reported that people with SCI, especially high lesion quadriplegics, demonstrated a marked reduction in the need for sexual stimulation and displayed less anger while exhibiting an increase in affection and sentimentality. He believed that the disruption to the autonomic nervous system (ANS) decreased negative emotional feelings and may contribute to a decrease in depression for people who experience a SCI. Horowitz, (1987) and Damasio (1994) theorise that this disruption acts as a “buffering effect.” They claim that when a person’s ability to cope is exceeded by the pressures and stress exerted by the environment, the person stores this affect or emotion in the brain, remaining dormant, “frozen in time,” until a future event would trigger its release.

A SCI is one of the most stressful and traumatic things that can occur to a person because it affects every aspect of a person’s life and is never over. Heim, Owens, Polotsky, and Charles (1997) found that women who experienced early trauma reacted to experimental stress with elevated stress hormones. The women who were currently experiencing major depression recorded the highest output of stress hormones. It is believed that, because of genetic differences, some people have a biological vulnerability to depression (Heim et al., 1997). If these people, who are vulnerable, experience stress at an early age, it is believed that it pre-deposes their brains to permanently over-react to environmental pressures (Heim et al., 1997). Duman (1998), Duman et al. (1999) and McEwen (1999) found that stress, environmental or social, could actually reduce the number and size of neurons in the hippocampus. This reduces the production of brain-derived neurotropic factor (BDNF) that strengthens synaptic connections in the
hippocampus, thus causing a reduction in the growth of neurons that respond to serotonin. McEwen (1999), Drevets and Raichle (1998), and Drevets (1999) reported that the prefrontal cortex and the amygdala were smaller in people who were depressed. It appears that, when a person experiences stress, there is a release of corticotropin-releasing factor (CRF) which acts on various sites throughout the brain and the body, including the hippocampus, prefrontal cortex, and amygdala. The left prefrontal cortex acts to help a person concentrate and attain positive goals and inhibits the amygdala.

When the CRF flows through the brain and the body, it triggers a hormonal cascade that creates the symptoms of depression and malaise. Davidson, Abercrombie, Nitschke, and Putnam (1999) found, that when this occurred, the left prefrontal cortex, which usually works in harmony with the amygdala, shuts down and the amygdala is allowed to work uninhibited. The amygdala controls negative emotions and scans incoming experiences and, without the inhibiting factor of the left prefrontal cortex, goes into overdrive and sends the brain and body into depression. The hormonal balance of the body is now out of control and the increase in the glutamate over-stimulates neurons to the point where their dendrites collapse and shrink. McEwan (1999) found that prolonged stress destroys cells in the hippocampus, precipitating cognitive decline. Clause-Walker and Halstead (1981, 1982a-d) found that there was a profoundly altered endocrine function early in SCI. Davidson et al. (1999) found that, during periods of helplessness, blood flow was increased in the amygdala. Selye’s General Adaptation Syndrome (GAS) states that, if a stress is not removed, the person’s resources eventually become depleted and the person hits a state of exhaustion where he or she is unable to cope (Selye, 1976). Frank, Elliott, Cochran, and Wonderlich (1987) found that life stress in people with SCI was not
reduced with the passage of time. They found that those people with SCI who experienced stressful events beyond their SCI scored much higher in tests of depression. They speculate that SCI reduces the ability of a person with a SCI to cope with stress. If high levels of stress are maintained over a protracted length of time, the body may create somatic disorders (Kathol, 1985) such as heart disease (Glassman, 1998) and osteoporosis (Michealson & Gold, 1998). This prolonged stress may cause depression or malaise creating further problems because people who are depressed tend to eat poorly and usually avoid physical activity. This weakens the body and allows the person to be more vulnerable to disease (Kathol, 1985).

Charlton and Ferrier (1998) maintain that depression does not simply have physical concomitants but is a wholly physical disorder where sickness is read as sadness. A low mood or malaise identified by symptoms similar to depression like lack of energy, slowed movement, lack of concentration, and inability to experience pleasure may actually be secondary somatic responses to sickness or an injury like SCI. Sickness is misread as sadness and the brain is inappropriately activated to begin and sustain a hormonal cascade that triggers depression. Damasio (1994) theorises that feelings are the brain’s representation of what is happening in the body. He claims that the prevailing body state at any moment colours all incoming perceptions. If the prevailing state is sadness, then incoming memories are encoded and stamped as aversive. When these memories are summoned, then the emotions of sadness are linked to them and the person’s experiences of malaise and depression are linked to these memories. The person is unable to even imagine anything that could make him or her feel motivated and is overcome with a feeling of despair and hopelessness (Damasio, 1994). Healy (1997) goes
further by stating that depression is even more than a disorder of the whole body but a
disorder of the whole person creating feelings of distress, unhappiness, and hopelessness
at the existential and social levels of existence. If the stress exceeds the body’s capacity
to cope, then the affect, which is being experienced at that time, is stored in the brain and
the body (Hohmann, 1966; Damasio 1994). The emotions that were present when the
“buffering effect” stored the affect would remain dormant and not effect the stress level
of the person until triggered by a later event (Damasio 1994; Horowitz, 1986). Once
triggered and released, the affect would be experienced as if it were fresh and could
create an emotional response sufficient to create a depressive state in that person.
Depression, in SCI, may be an organic reaction to stress where the brain reads sadness for
a physical sickness.

SCI is expensive and not having enough money creates stress and problems with
quality of life. The constant stress is often exhibited in the form of physical ailments and
diseases. People with SCI are much more likely to have somatic problems like cancer,
MS, diabetes, heart disease, pneumonia, and renal failure (Glassman, 1998; Kathol, 1885;
Knight, 1989; Michealson & Gold, 1998; Trieschmann, 1988). These diseases can be, in
part, attributed to physical complications but stress exacerbates all of the physical
problems of SCI. Much of the stress, after the initial spinal shock wears off, is from
environmental and psychosocial sources.

Environmental Factors Involved In SCI

There are many people who believe that the very concept of disability is a social
construction (Oliver, 1988). Webster’s dictionary defines disability as, “That which
disables or disqualifies” (Simon & Schuster Inc., 1984, p. 65). Finkelstein and French (1993) define disability as:

The loss or limitation of opportunities for a person with an impairment to participate fully in the normal life of the community on an equal level with others due to a physical or social barrier. (p 23)

They also define a physical impairment as, “The lack of part or all of a limb or having a defective limb, organ, or mechanism of the body”(p. 23). Oliver (1993) claims that the term, disability, is not clearly definable because the definition of disability is a political statement. Oliver (1988) maintains that it is the physical and psychosocial environment that creates the concept of disability because they exclude people outside of a narrow definition of what is normal, including people with SCI, from a full and equal participation. The physical environment creates disability because of the design of buildings and cities. Buildings are designed with revolving doors, stairs, escalators, inaccessible washrooms, narrow doors and hallways. Many stores have aisles that are too narrow for a wheelchair. Kitchens are designed so that it is nearly impossible for a person in a wheelchair to use the countertop, cupboards, sink, or any of the appliances. Many tourist attractions and theme parks have pathways and entrances that are not accessible to people in wheelchairs. Sidewalks are sloped and often there are no curb cuts. Each time people in wheelchairs are faced with physical barriers that they cannot deal with on their own, it acts as a re-enforcer and a reminder of the fact that they are not normal, and that they are disabled. It is theorised that, if the environment was made completely wheelchair friendly and if people with SCI had the proper equipment, they would not be physically disabled (Oliver, 1988). This theory assumes that individuals with a SCI can totally control their physical environment at all times. This is not always possible. For example,
a person with a SCI who has a total lesion at C-5 uses an electric wheelchair and is able to transfer in and out of bed himself but he is unable to transfer from the floor to the bed or a chair. He can perform all of his own aids to daily living requirements including dressing, grooming and meal preparations. He is going from his living room to the kitchen and suddenly the electric chair breaks down. The question arises, “Is this person disabled?”

The physical environment is in real space and time. People with a SCI must interact with space and time differently than they did before their accident and differently than most people around them. It is difficult to be spontaneous. Planning is required to meet for lunch, travel, or have a sexual relationship because of transportation, bowel routines, catheters, and medications. It is difficult for individuals with a SCI not to compare themselves with other so-called normal, able-bodied people or to what they could do before their accident.

Effects Of The Environment In Rehabilitation

The rehabilitation setting is theoretically set up to help individuals, with a SCI, recover physically from their accident and enable them to reintegrate back into the community. To do this efficiently, the patient is put on a strict routine and regime. This is effective in taking care of the patient’s physical needs but ignores the psychological needs and seriously compromises the goal of helping the patient become independent.

Patients with a SCI, in rehabilitation, have little impact on their environment. They lose control of their ability to bring themselves pleasure and to avoid discomfort (Trieschmann, 1988). For example, they must use a hospital bed instead of their own bed. Patients lose control of their customary life style and must fit into the routine imposed by
the hospital. They are expected to be energetic during Recreational Therapy time and quiet and peaceful at bedtime regardless of their individual desires (Trieschmann, 1988). The hospital environment is set up for the convenience of the staff and for efficiency and is often at odds with a patient’s personal schedule. This creates the feeling that the person has lost control of his or her life. The hospital schedules when a patient with a SCI will sleep, eat, go to physiotherapy, shower, be catheterised, have bowel routines, be turned, and receive medication (Trieschmann, 1988). The patient is not given any warnings about any medical procedures such as X-rays, EKGs or other tests. This heightens anxiety because of the fear of the unknown. Suddenly the person with a SCI is in an X-ray room wondering what the implications of this test will be and if there is something else wrong with him or her (Trieschmann, 1988).

The goals of the SCI patient and the therapists are often different. Taylor (1974), in his study on quadriplegics and occupational therapists, found that the main goals of the therapists were:

1. development of adaptive equipment
2. eating and socialisation
3. wheelchair mobility
4. writing (typing)

However, the main goals of the quadriplegics were:

1. work tolerance
2. muscle strengthening
3. bowel and bladder care
4. wheelchair mobility

The most important goal for the Occupational Therapists, development of adaptive equipment, was 13th on the list of goals for the people with quadriplegia. This study demonstrates that often there is a lack of communication between the patient and the
therapists about goals and expectations in the rehabilitation setting. Glass, Krishnan, and Bingley (1991) added that it was a source of frustration when the goals of the medical staff and those of the patients were not in agreement. Ohry (1987) states that patients found that the adaptation devices were alienating and stigmatising. Patients thought that adaptive devices damaged their body image and created adverse reactions from family and friends. Although the adaptive device may have improved function, it acted as a constant reminder of the patient's lack of ability and normalcy. Trombly (1966) found that the less the patient with a SCI tried the more attention he received from the nurses and therapists. Thus, the therapist unwittingly reinforces dependent behaviour that is counter-productive to the goal of independence. Patients who display independent behaviours, such as staying up late at night or not being completely compliant, are often punished and labelled as trouble-makers when, in fact, their behaviour could be explained as them striving to have some sense of control of their environment. Patients are forced to comply with the system because if they don’t, they are labelled as troublemakers who are not adjusting well to their injury.

Individuals with a SCI suffer a loss of self-image and self-esteem because of the objectification and de-humanising effect of the way they are treated by the doctors and the nurses in the rehabilitation setting. Weil (1995) refers to this as the NOCEBO effect or the negative placebo effect of the western medical model of health care. Sometimes the sheets will be pulled back exposing the patient to the entire group if he or she has some condition of particular interest. The patient is talked about and talked over but not to Halstead et al. (1986) stated:

Although we do not feel this traditional method of rounds is appropriate, even in acute general hospitals, it seems even less appropriate in dealing with rehab-
patients within the context of the philosophy that rehabilitation is a teaching/learning process that involves the active inclusion of the patient in an interdisciplinary effort. (p. 360).

The routinisation and de-humanising treatment of the patient in the hospital contributes to feelings of loss of self-esteem and confidence and fosters a dependency on the routine, which can lead to a lowered responsiveness and decreased energy (Trieschmann, 1988). This may lead to a person being reluctant to go on outings or be involved in anything that is new or different because he or she has become dependent on the “routine.” Cross (1986) states that the context defines the behaviour of the patient. The patient is sick and vulnerable. He is lead to believe he is lucky to be there. The patients with SCI are often dealing with feelings of guilt and shame and, if they dare to protest about anything, they are labelled as not adjusting well and are punished by having services delayed or forfeited. In this way, the system starts shaping the behaviour of the patients. The services in the rehabilitation setting have been built up around professional skills rather than on the clients’ needs (Oliver & Hasler, 1987).

Secondary Losses

A SCI is devastating because it ultimately affects every aspect of a person’s life. This occurs because of the secondary losses it indirectly causes. When individuals with a SCI are in rehabilitation, they often lose their employment. With a loss of employment comes a loss of income. This creates a decrease in status and prestige. Individuals with a SCI go from being the person who is the provider to a person who is being cared for. This shift in roles and status is occurring at the same time that the person with a SCI is attempting to deal with spinal shock and the loss of physical abilities. During the first year of rehabilitation, a person with a SCI usually experiences a loss of friends and
acquaintances (Goffman, 1963; Jones et al., 1984). There is also a significant increase in the divorce rate for people with SCI (Jones et al., 1984). It appears that the most traumatic psychological experiences of SCI occur within the first few months after the accident. The concentration in rehabilitation in the western medical model at this time is on physical recovery. However, during this stage of rehabilitation little time is spent on the psychological or social rehabilitation of people with a SCI (Trieschmann, 1988). Bracken et al. (1981) contends that this period of time, the first few months after the accident, is the most critical time for psychological intervention. The question then arises as to exactly what interventions would be most effective because there is little evidence to show that present interventions in rehabilitation result in long term adjustment to SCI (Craig et al., 1990; Dobkin, 1994; Winneman, Durand, & McCulloch, 1994).

Psychosocial Factors

Psychological adjustment rather than a person's intellectual capacity or the level or completeness of the break was the critical factor in determining if a person with a SCI adjusted to his or her SCI and rehabilitated successfully (Hablin, 1968). Hablin (1968) felt that, without acceptance of the SCI, the best physical therapy or vocational training was of little benefit. Corbett (1980) stated that if a person with a SCI did not adjust to his or her new sexuality that counselling in other areas seemed to be of little benefit to him. Other studies further demonstrate that there is no correlation between level of break and completeness of break and adjustment to SCI (Kennedy, Gorsuch, & Marsh, 1995; Knight, 1989). This is counter-intuitive because one would assume that a person who was a complete quadriplegic would have more psychological problems and issues than a partial lesion paraplegic. In fact, the literature on suicide for people with SCI
demonstrates that people with complete quadriplegia have the lowest suicide rate and that people with partial lesion paraplegia have the highest rate (De Vivo, Black, Richards, & Stover, 1991; De Vivo, Kartus, Stover, Ruti, & Fine, 1989).

There is a tendency for able-bodied people to stigmatise people in wheelchairs and conclude they are a homogeneous group (Trieschmann, 1988). There is a tendency to either overestimate or underestimate the abilities of a person in a wheelchair because of the limited number of observations and contacts able-bodied people have with them. For example, not all people in wheelchairs want to or are able to play wheelchair basketball.

People without a SCI often overestimate the presence of psychological problems among people with SCI. This is well demonstrated by a study conducted by Taylor (1967) using the Minnesota Multiphasic Personality Inventory (MMPI). Taylor had one group of experienced rehabilitation workers, one group of naïve able-bodied volunteers, and a group of young men with SCI. The two able-bodied groups were to write the test as a person with a SCI would. The group with a SCI would write for themselves. The group with the SCI scored within the realm of normalcy for the MMPI. However, the results of the scores on the MMPI for the two able-bodied groups showed considerable pathology including such things as depression, alienation, anxiety, and lack of self-confidence. Other studies by Albrecht and Higgins (1977), Caplan (1987), and Lawson (1976, 1978) demonstrated that able-bodied people including rehabilitation workers, doctors, and nurses perceive people with SCI differently than the people with SCI perceive themselves.

There is also a tendency for the able-bodied community to assume homogeneity of response to SCI. There is an assumption that a person with a SCI must go through an
ordered series of emotional states such as denial, anger, and depression. This is not supported by research (Shontz, 1984). In fact, studies by Cook (1979); Fullerton, Harvey, Klein, & Howell (1981); Howell, Fullerton, Harvey, & Klein (1981), Judd, Burrows, & Brown (1986), Lawson (1976), and Thompson and Dexter (1980) demonstrate that people with SCI were no more depressed than able-bodied people who had the same age and background. There does not appear to be one type of personality associated with SCI (Cook, 1976; Shontz, 1971; Siller, 1969; Trieschmann, 1988; Wright, 1980). These studies also demonstrated that there is no consistent pattern of emotional response to SCI and that people with SCI react differently to their disability.

Able-bodied people are often confused by the reaction that individuals with a SCI have to the trauma of their SCI and confuse hope with denial and depression for grief. Hope is a positive human emotion and grief is a normal emotional reaction and response to a traumatic loss. Grief is not pathology and should not be equated with depression (Fullerton, et al., 1981; Judd, et al., 1986). Each person with a SCI deals differently with trauma on an emotional level. Psychopathology in people with SCI is rare as are stages of reaction and grief is usually resolved with time (Trieschmann, 1988).

Dealing with a SCI is a lifelong process. There is no endpoint where all is well and conflicts between desires and abilities are resolved (Cook, 1979). Dealing with a SCI is a lifelong battle, a monumental inconvenience (Corbett, 1980). Hablin (1968) believed that psychological adjustment rather than a person's intellectual capacity or the level of break or completeness of break was the critical factor in determining if a person rehabilitated successfully. He claimed that, without an acceptance of the SCI, the best physical therapy or vocational training was of little benefit (Hablin, 1968).
Quality Of Life In SCI

Research has demonstrated that the presence of a physical impairment is not a detriment to a full life that would include happiness and sadness; accomplishment and losses; and satisfaction and frustration (Brown, Gordon & Rognarsson, 1987). Quality of life is a difficult thing to evaluate because it is largely a matter of perception. Ferrans and Powers (1992) define Quality of Life as, “A person’s sense of well being that stems from satisfaction or dissatisfaction with the areas of life that are important to him or her” (p.29).

There will be people with SCI who have money, relationships, and high function for whom it is not enough and thus they become depressed; then there will be the people with SCI who have little money, are alone, and are low functioning for whom it is sufficient and they are happy. How can this discrepancy be explained? Oliver (1988) states:

The relationship between the individual and society cannot simply be understood as a function of the impairment of the individual and the extent of the social restriction that the impaired individual faces. There is an intervening variable which needs to be considered which can be called meaning. (p. 11)

Frankl (1984), in his theory of Logotherapy, maintained that it was not the significance of the event but the significance the person attached to the event that gave it meaning. Oliver (1981) maintained that experiences are not fixed or stable and Engel (1964, p. 42) stated, “It is not the circumstances of life but one’s attitude towards those circumstances that seals one’s fate.” People with a disability can choose how to negotiate their own way through these events. These negotiated passages are not determined by events that occur (e.g., paralysis as a result of an accident) but only by the meaning that individual attaches to these occurrences (p. 52). Oliver (1981) proposed that these meanings were not solely a product of the individual’s consciousness but are a product of
the individual in interaction with other people in the environment. Quality of life then would be based on individual’s perceptions of what quality of life is for them instead of some quantitative arbitrary standard. This perception or cognitive reality would be formed by the person’s pre-morbid personality acting as a filter to interpret and attach meaning to his or her experiences in the physical environment and with interpersonal relationships with the people in that environment.

It appears that the most important factor contributing to quality of life for people with SCI is financial security (Brown et al., 1987; Trieschmann, 1988). Financial security allows individuals with a SCI to control their environment. With sufficient money, they can remove physical barriers, hire sufficient help, and provide themselves with transportation and mobility. When men with a disability had resources, they allocated their time similarly to the normal able-bodied population (Brown et al., 1987). Flanagan (1982) identified the following factors as being important contributors to quality of life:

1. Material comforts
   a. home
   b. conveniences
   c. increasing income
   d. security
2. Work – in a job that is interesting
3. Good health and personal safety
4. Recreation
5. Learning
6. Relationships
7. Socialising
8. Creativity

George and Bearon (1980) defined Life Satisfaction as a match between personal goals and being able to achieve those goals. They defined self-esteem as a judgement arising out of a comparison of what people feel they are like in comparison with what they aspire to be. George and Bearon (1980) maintained that the main variables in quality
of life were life satisfaction, self-esteem, health and functioning, and socio-economic status. Glass (1994) believed that quality of life is a cognitive exercise determined by a judgement and evaluation of an individual's financial security, satisfaction, and the degree and quality of social interaction and support. The judgement and evaluation of these factors is a function of the person's pre-morbid personality. It is from this position of prejudice that people attach meaning to their experience of SCI.

Moos (1982) stated that people respond differently when put into a trauma situation. He believed that if the equilibrium were breached between the person's background, illness related factors, personal factors, and social environmental factors, the individual would not be able to resolve any conflicts. Adjustment then was a restoration of the equilibrium of the conflicts that presented themselves in these areas (Moos, 1982). Adjustment then is a psychological mechanism for managing external stress (Lazarus & Folkman, 1984). Cohen (1987) defined adjustment as a mechanism that may be both action-oriented and intra-psychic and is intended to avoid or mitigate the consequences of a stressor. The problem is that a SCI causes a disruption or a disequilibrium in every dimension of a person's life (Hablin, 1968; Knight, 1989; Trieschmann, 1988). These disruptions never end because there is no end point where everything returns to normal. This causes many people with SCI to say they will never adjust because adjustment implies acceptance, a situation they never wish to achieve. They prefer to use terms such as "tolerate" or "accommodation" (Glass, 1994).

There have been many attempts to establish if there are specific types of personality variables that act as predictive indicators of response to trauma and successful or unsuccessful adjustment to trauma. The research in this area has produced
inconclusive results (Ducharne & Freed, 1980; Weller & Miller, 1977). Glass (1994) maintains that failings in this research revolve around the fact that there is a lack of standardisation of data sets and the research fails to address the subjects' pre-morbid levels of adjustment and their environmental and contextual situation that was in place before the traumatic event.

Long-Term Adjustment To SCI

Adjustment or coping with the trauma of a SCI is a dynamic on-going process that never ends and changes over time (Hansen, Buckelew, Hewett, & O'Neal, 1993; Winneman et al., 1994). Coping behaviour has been found to be situation specific and based on the context in which the person-environment transaction occurs (Folkman & Lazarus, 1988; Lazarus & Folkman, 1984; Rosenteil & Roth 1981; Taylor, Bogdan, & Racino, 1991). The kinds of coping behaviour used to manage situations encountered by healthy individuals (Folkman, Lazarus, Dunkell-Schetter, DeLongis, & Gruen, 1986) or those newly diagnosed with cancer (Mishel & Sorenson, 1993) are different from coping behaviours used by community populations with long-term chronic conditions (Winneman et al., 1994). Winneman et al. (1994) states that the options that a person has to use for coping behaviours depend on the individual’s physical, social, intellectual, financial, and other personal resources and attributes the person possessed before the trauma occurred.

It is the person’s pre-morbid coping skills, attributes and resources that determine the person’s capacity to initially cope with a stressful situation. It seems that a mature ego is more able to adapt to stress better than an immature ego (Erickson, 1982). Erickson (1982) found that the development of the ego was more dependent on development from
within and surprisingly independent of social and genetic factors. Vaillants (1977) stated that maturing patterns of adaptation depend as much upon biological as on psychosocial factors. It appears that close relationships and not our culture shape our adaptive resources. In turn, adaptation further enhances relationships (Vaillants, 1977). Vaillants (1977) believed the ability to develop mature patterns of adaptation were largely the result of close and loving relationships in childhood. Haan (1993) believed that the maturation of adult ego defence mechanisms developed over time and that as the ego matured that reaction formation and fantasy declined and altruism and suppression increased and were used with greater frequency.

When a person experiences SCI, it stretches his or her capacity to cope and adjust to this trauma. If the trauma exceeds the person's ability to cope with the stress he or she may exhibit some or all of the following behaviours:

- pressure of talk
- avoidance
- withdrawal and isolation
- inappropriate behaviour (sexual acting out)
- self mutilation (hitting self on legs)
- obsessive compulsive behaviour (using drugs, alcohol, sex)
- fragmentation
- dissociation
- emotional display
- flashbacks, nightmares, hallucinations
- re-experiencing phenomenon

(Briere, 1992; Linehan, 1993; McCann & Pearlman, 1990)

The trauma from a SCI can place a person in a state of disequilibrium severe enough to plunge a person into what Welwood (1982) identifies as world collapse. Where there is a shattering of his or her ego, self-esteem, and self-image. Suddenly the world as he or she knew it is gone forever, collapsing into a void of transitory nothingness (Welwood, 1982, p. 125). Nishitani (1982) refers to this experience as:
A gaping abyss opens up at the very ground on which one stands. In the face of this abyss, not one of all the things that had made up the stuff of life until then is of any use. (p. 3)

The experience of world collapse creates a shift in our approach to existence from one of a self-centered mode of being in which we ask what use things have for us to asking what is our self-existence all about (Nishitani, 1982). This annihilating moment of world collapse renders meaningless our pre-determined meaning of life.

This feeling of world collapse is created if the stress in the situation exceeds the person’s capacity to cope with that situation. Then, the person is thrown into disequilibrium and experiences trauma. The level of stress or anxiety is determined by the meaning or significance that the loss has to that individual. The trauma and subsequent losses can seriously affect a person with a SCI’s quality of life and life satisfaction. However, one of the problems with quality of life, life satisfaction, or self-esteem is that an observer can’t measure them objectively. Therefore, there is no standardisation of measures of quality of life and related measures. Quality of life and self-esteem are subjective and are an interpretation of a person’s general sense of wellbeing and self-worth (George & Bearon, 1980). This makes it difficult to evaluate the intensity of the trauma because it is dependent on the meaning the loss has to that individual. The problem is that the person’s belief system has been shattered and the very ground upon which he or she stood has been ripped apart. He or she now lays a prisoner unable to move or function, staring into an abyss where his or her whole concept of reality has been destroyed. Nothing in his or her previous life has prepared him or her for this reality. There is no way to ward off anxiety because everything has changed and nothing will ever be the same again.
Briere (1996) theorises that individuals accommodate traumatic distress through the application of pre-morbid coping skills, self-resources, and capacities. These resources and coping skills are developed in a normal parent-child attachment experience (Alexander, Sipski, & Findley, 1992). These resources are developed from childhood. The development of these coping skills is a process that allows a child to gradually learn to cope with surmountable challenges from a position of external security (Bowlby, 1982). The child learns to deal with internal states of disequilibrium through a process of trial and error. Slowly the child develops a progressively more sophisticated set of internal coping strategies and an increased ability to tolerate greater emotional pain. A person's ability to tolerate and moderate distress is dependent on the successful learning of these skills in an environment where challenges are surmountable and the discomfort level does not exceed the individual's growing internal resources. This growing affective tolerance is thought to be self-sustaining (Bowlby 1982). Briere (1992) refers to affect tolerance as the individual's relative ability to experience substantial negative affect without having to resort to the use of psychoactive substances or to engage in external activities such as aggression, self-mutilation, sexual acting out, or any other self-destructive behaviour (Briere, 1992). When our personal resources are exceeded by trauma, it may result in the destruction of self by destroying an individual's self identity, personal boundaries, and affect regulation (McCann & Pearlman, 1990).

When individuals have a strong personal identity, they can respond to a severe stress by being organised and able to place the stress in the proper context without confusion or distortion (McCann & Pearlman, 1990). However, if the trauma is too severe, they can become overwhelmed and lose their identity (Hamilton, 1988). They can
be fragmented and experience a separation of their mind-body-spirit connection and lose awareness of their goals, needs, perspective, and entitlement (Hamilton, 1988). They may also experience dissociation, which is an alteration of normal links between thoughts, feelings and memory (Briere, 1992). There is evidence that trauma and abuse can distort individuals’ perception and understanding of self. This can cause them to believe they are inadequate, loathsome, and deserve to be treated poorly (Roboff-Bulman, 1992; Jehn 1988; Peterson & Seligman, 1983). If the abuse or trauma is severe enough, it can become internalised as an enduring negative cognitive schemata (Briere, 1996).

If the trauma is severe enough individuals may also lose awareness of the personal boundaries between themselves and others (McCann & Pearlman, 1990). They lose the sense of where their own needs, identity, and perspectives end and other people’s begin. They allow other people to intrude into their boundaries and victimise them by abdicating the ability to negotiate for what they want, to seek help, and to be assertive (Elliott, Marmarosh, & Pickelman, 1994).

The final part of self that appears to be seriously disrupted by trauma is affect regulation. When individuals are put under extreme stress and anxiety due to trauma, they no longer can control affect modulation or affect tolerance (Briere, 1992; Linehan, 1993). They allow themselves to exhibit inappropriate emotional displays of anger and sentimentality in situations where the display of these emotions is unwarranted.

There appear to be many inconsistencies and paradoxes in the literature on SCI. These inconsistencies make it difficult in determining which coping skills and attributes are the most effective in promoting long-term adjustment to SCI. The areas around which
there seem to be the most inconsistencies and discrepancies are depression, self-blame and relationships.

There has been extensive research in SCI around the topic of depression. Studies have demonstrated that people with SCI are no more depressed than the general population (Cook, 1979; Fullerton et al., 1981; Howell et al., 1981; Judd et al., 1986; Lawson, 1976; Thompson & Dexter, 1980). Green, Pratt, and Grigsby (1984) found that people with SCI had higher scores for moral, ethical, social, and personal self while they scored lower on the scores for physical self. By contrast, Mayer and Eisenburg (1982) reported that people with SCI had no difference in self-concept with the normal population. However, Hanson et al. (1993) reported that distress among survivors of SCI five years after injury were 29% higher than in the normal population. Krause et al. (1997) linked depression with SCI, claiming that depression in SCI led to self-destructive behaviour with drugs and alcohol, poor hygiene, poor nutrition, and generally poor self-care that resulted in an increase in pressure sores and disease. Malec and Niemeyer (1983) found that scores on depression were predictive of bladder and skin care in people with SCI. Hancock, Craig, Tennant, and Chang (1993) found that people with SCI were more external in their concept of control, scored lower in measures of self-esteem, and had higher scores in hopelessness and amount of fantasies. These scores did not change over a one-year period. Depression was found to seriously affect the learning and motivation of people with SCI (MacDonald, Nielson, & Cameron, 1987; Trieschmann, 1988). Elliott et al. (1991) found that people with SCI who were depressed did not experience hope. They seemed to lack the will or desire to accomplish any goals or they seemed unable to visualise a pathway for accomplishing these goals that were a cognitive
reality. Craig et al. (1990) found that depression in people with SCI did not resolve over time.

It is during the first year of a SCI that the most serious psychological disruptions occur (Bracken et al., 1981). Bracken et al. (1981) states that at the time of discharge many people with SCI have serious problems with anger, anxiety, and depression that have not been addressed in the rehabilitation setting. Usually people with SCI are discharged from the hospital when their bodies have healed and they have the physical skills to leave. The problem with this is that they usually have not developed a new self-identity and incorporated the new set of “I am” into the way they socially interact with the world and the environment (Albrecht & Higgins, 1977).

Individuals with SCI interact differently with their environment than their able-bodied counterparts. People with SCI view themselves differently and are perceived as being different, thus requiring a different set of social skills. One of the most difficult areas of re-integration is with the families’ reaction to a SCI (Albrecht & Higgins, 1977). People with SCI must face the problems of negative affectivity (people doing too much for them) and a changing role definition from one of provider to one of being provided and cared for. Society demands that individuals with a SCI act normal when personal experience demonstrates that they’re not (Caywood, 1974). Bracken et al. (1981) maintain that the necessary social skills needed to cope with reintegration should be taught and mastered in the rehabilitation setting with counselling. However, there are no long-range longitudinal studies that can accurately predict which coping skills will work with which people with SCI in which situations (Craig et al., 1990; Dobkin, 1994; Winneman et. al, 1994).
The literature on self-blame is a perfect example of this. Hansen et al. (1993) found that people with SCI who did not blame themselves for their accidents scored higher on adjustment in early rehabilitation than people with SCI who accepted blame for their accident. However, five years later, the people with SCI who blamed others for their accident scored significantly lower on scores of adjustment while people who accepted responsibility for their accident scored higher on scores of adjustment. Furthermore, the low scores on adjustment, early in rehabilitation, for the people with SCI who accepted self-blame, were not predictive of long-term adjustment. Other studies have demonstrated that self-blame is not predictive of adjustment (Heinemann, 1986; Shultz & Decker, 1985). Sholomskas, Steil, and Plummer (1990) also found that self-blame was not predictive of adjustment but that blaming others was a strong predictor of not adjusting to a SCI. It appears that instead of worrying about whom to blame for the SCI the issue of accepting the responsibility of taking care of oneself is more critical to long-term adjustment to a SCI.

Relationships and social support have been found to have a paradoxical relationship to adjustment to SCI (Damasio 1994; Horowitz, 1986). Many field studies have demonstrated that elements of social support have a positive effect on adjustment to SCI (Coyne & DeLongis, 1986; Elliott, et al., 1991, Elliott, Herrickk, & Witty, 1992; Rintala et al., 1992; Schulz & Decker, 1985). However, there is evidence that social support may become a source of stress to people with a SCI (Fiore, Becker, & Coppel, 1983; Rook, 1984). Institutional support may increase feelings of devaluation and rejection in people with SCI (Dunkell-Schetter & Wortman, 1982). Supporters may become over-involved, intrusive, and overprotective; make insensitive comments that
might discourage autonomy and personal responsibility (Coyne & Delongis, 1986; Lehman, Ellard, & Worman, 1986). Significant others often exhibit contradictory emotions and express these feelings and reactions in ambivalent expectations and behaviours towards a person with an illness (Wortman & Conway, 1985). Intimate relationships may inadvertently reinforce dependency by being over-responsive to a loved one’s condition (Flor, Turk, & Rudy, 1989; Turk, Kems, & Rosenberg, 1992). Crewe, Athelstan, and Krumberger (1979) found that men with SCI who were in pre-injury marriages and stayed married were more likely to be impaired in activities of daily living because their partners tended to help more than the partners of men with SCI who were married post-injury. It appears that men with SCI involved in satisfying intimate relationships evidenced more psychosocial impairment the longer the time passed since the onset of the injury (Elliott et al., 1992). There is also evidence that suggests that support may wane over time as resources are depleted and overwhelmed (Brown, Wallston, & Nicasso, 1989; Fontana, Kems, Rossenberg, & Colonese, 1989; Hobfall & Lerman, 1989). Social supports may be linked to health complications but the exact way that social support interacts with and affects adjustment to SCI has not yet been clearly delineated (Elliott et al., 1991). Krause et al. (1997) found that reliant alliances, increased attachments, and increased nurturance increased the impairment of a person with a SCI over time. There is also evidence that assurances of worth and guidance decreased impairment of a person with a SCI as time passed from the time of injury (Crewe & Krause, 1987; Fine & Asch, 1988; Herrick et al., 1994; Damasio 1994). Assurances of worth that reinforced competencies, skills and abilities decreased depression in people with SCI (Herrick et al., 1994). Herrick et al. (1994) found that older people with SCI had
more problems with self-care than younger people did and that paraplegics had more problems with skin care than quadriplegics. Social support can have a positive or negative effect on a person with a SCI depending on how the person with the SCI interacts with the people in a particular environment and situation. The paradoxical nature of relationships is that if people with a SCI withdraw and isolate themselves, they have a good chance of becoming depressed. However, if they form an intimate relationship, they then run the risk of negative affectivity. The result of each scenario is the same, that is, poor self-care and psychosocial impairment.

Sexuality And SCI

SCI appears to be perceived as mainly a physical trauma in the rehabilitation setting with less attention given to the psychological or social disruptions that accompany it. Romeo (1993) found that people with SCI generally had problems with body image but that their sex drive and satisfaction with sex were equal with the able-bodied population. Hablin (1968) stated that if an individual with a SCI did not accept his or her new sexuality, all the physical therapy and vocational counselling would be of little value. Hablin (1968) further stated that psychological adjustment was more critical than intellectual capacity or the level of incapacitation due to a SCI. The loss of bowel and bladder control, the inability to walk, and increased dependency can cause a person with a SCI to experience feelings of shame and inferiority (Singh & Magner, 1975). There are also alterations in perceptions of body image and with one's bodily capabilities that are usually negatively impacted by SCI, which coincide with reductions in self-esteem and difficulty in readjustment (Derogatis, 1980; Romeo, 1993). Further distortions in body image can occur because of the absence of normal sensory input (Tucker, 1980).
definition of male sexuality has revolved around the concept of sexual performance that involved erection, ejaculation and fertility as the definition of male masculinity. The loss of these abilities is generally seen as devastating to men with SCI (Teal & Athelstan, 1975). These effects are especially devastating when it is realised that most men with SCI placed a very high value on physical activity in their pre-trauma life. Romeo (1993) concluded that because men with a SCI could not fulfil the performance requirements of erection, ejaculation, and fertility, they needed to expand and reconstruct a view of self and sexuality that would include them as males. Farrow (1990) stated, “If a man with SCI is to begin to re-establish himself as a man, he must first learn to expand his view of masculine behaviour” (p. 257). There is a fine line between a healthy re-assessment of masculine sexual behaviours and a person with a SCI making a self-perception shift towards more traditional feminine behaviours, or a shift towards a passive “demasculated” state described by Teal & Athelstan (1975), which could be perceived as a negative adaptive behaviour. This brings up the issue of exactly what is male or female sexual behaviour and whose perceptions of those boundaries are we using?

The problem in many rehabilitation centres is that, when questions of which issues of psychosexual adjustment should be addressed, the decisions are based on clinical judgement rather than on sound scientific conclusions (Willmuth, 1987). There are considerable problems in research design in the study of SCI which lead to many confounding conclusions (Craig et al., 1990). To make sense of the literature and to get “at” the topic “Understanding the trauma of SCI,” it was necessary to develop a methodology that could successfully accomplish this task.
CHAPTER THREE
RESEARCH METHODOLOGY

When considering how best to explore the topic of trauma and what happens inside the mind of a person recovering from SCI, a decision had to be made whether to do the study in a qualitative or a quantitative manner. I will first examine why quantitative research methodologies were rejected. Then I will explain why phenomenology and hermeneutics were used to interpret the narrative of the participants. I then consider why it is important that this research be respectful of the fecundity of the individual story. I will use the literature, the stories of the participants, and my personal experiences to interpret and bring meaning to the stories using a process of phenomenological hermeneutics. I will discuss how validity and reliability are difficult to confer on this type of research and the problems this creates for the researcher. Once this overview of research methodology has been discussed, I will outline the actual research procedure including the selection of participants, interview procedure, compliance with ethical standards, problems that occurred, and how the data were analysed.

Why Qualitative Research?

In positivistic quantitative research, two assumptions are made, namely:

a) That all of the components of a study can be isolated, measured, reduced to numbers and statistically analysed.

b) That the process can be done in an objective manner.

The idea that everything can be reduced to its simplest component and measured has been and continues to be questioned in natural sciences. Capra (1982) and Prigogine (1976, 1980), eminent scientists, put forth the theory that things cannot be reduced to their simplest form because all matter is interconnected at the sub-atomic level. Therefore, one
could argue that, if it is impossible to measure the exact number of particles and predict what these particles will do or even isolate them, then the scientist cannot accurately rely on scientific method to describe or predict an event or experiment. Natural phenomena are difficult to measure in a wide variety of circumstances. Therefore, it stands to reason that, in a social science setting, it is more difficult to quantify measure, and predict outcomes. For example, Patterson (1987), when answering the question “What specific therapeutic interventions produce specific changes in specific patients under specific conditions?” gave the following answer:

Before this model (relative to research) could be implemented, we would need (1) a taxonomy of client problems or disorders . . ; (2) a taxonomy of client personalities . . ; (3) a taxonomy of therapeutic techniques . . ; (11) a taxonomy of therapists; and a taxonomy of circumstances . . If we had such systems of classifications, the practical problems would be insurmountable. Assuming only five classes of variables, each with ten classifications . . a research design would require 10x10x10x10x10 or 100,000 cells. . . So, I conclude we don’t need complex multivariate analysis and should abandon our attempt to do the crucial perfect study of psychotherapy, it simply is not possible. (p. 247)

As Patterson so ably demonstrated, a complex human experience cannot be measured. Bollnow (1974) pointed out that “in the humanities what is essential is not measurable, and what is measurable, so far as this is such, is not essential but at best superficial” (p. 247). To attempt to understand the rehabilitation of a person with a SCI in a specific environment when all factors are taken into consideration would be more complex than the psychotherapy model put forward by Patterson. In the social sciences, attempting to quantify and measure a complex human experience would cause the researcher to lose the essence of what he or she was studying.

The second component of quantitative research is objectivity. Bollnow (1974) stated that “objectivity” is unbiased, unprejudiced, and impartial behaviour towards an
object. The ideology of objectivity not only sets up the parameters for the dominant positivistic research paradigm, but also effectively limits the scope for developing alternative methods of research (Zarb, 1992). In the positivistic research paradigm, in order to preserve “objectivity,” the subject is not consulted about the research in advance, about what issues should be investigated, or about how the research should be carried out (Oliver, 1993). Researchers would not want the results of their research tainted by any influences the subject might have on the results or the researcher’s interpretation of the results. This puts the researcher in the positivist paradigm, into the position of an outsider. When individuals are outsiders, Bollnow (1974) argued, it is impossible for them to be “objective” because they are already prejudiced. Outsiders often impose their views and causes the insiders to feel like they have the problem (Dembo, 1970). The outsider truly does not fully understand the experience of the insider, making validity difficult to obtain. The lack of experience, Bollnow (1974) stated, is comparable to a person being colour blind and trying to describe what a colour picture is like, while the subject, who is not colour blind would be seeing the picture in full colour. The perspective and understanding of the subject and the researcher about the subject’s experience in this situation would always be different. The researcher could also experience value blindness and meaning blindness because of the desire for objectivity (Bollnow, 1974).

I realised that I could never be objective about SCI because my recovery from quadriplegia over the past 15 years has left me with a prejudicial perspective, from living and experiencing the sequel of a SCI every moment of every day. Living with a SCI has affected every aspect and dimension of my life. This has allowed me to appreciate the
difficulty in researching and understanding this phenomenon. Krause et al. (1997), Jubala and Brenes, (1988), Judd et al. (1986), Knight, (1989), and Trieschmann, (1988) have all noted that little is understood about the psychological factors important to post-injury adjustment in SCI. It became apparent that someone who had experienced a SCI would have a tremendous advantage in understanding the trauma of SCI and the factors involved in post-injury recovery. My intent was to review the literature on SCI, interview men with SCI, and then using a phenomenological/hermeneutic approach, sift through the data and identify significant bits of information. These significant bits of data would be categorised and combined into clusters. These clusters would then be arranged and organised into a conceptual model and linked in such a way as to create a grounded theory. This method of generating grounded theory was developed by Schatzman (1991) and is called dimensional analysis.

Before we consider the qualitative aspects of this research, I will explain briefly my philosophical position in this research. When I started the research, I had my own preconceptions about trauma and its effect on consciousness. These biases have been challenged, supported, supplemented, provoked and changed by the ideas of my fellow participants, members of my thesis committee, and the literature on SCI, trauma, consciousness, and questing. In fact, the research process has been very cathartic. I am a different person from the person who started this project in 1993. Each new experience seemed to shift my understanding of my experience of SCI and of the world. Each new understanding would in turn alter my interpretation of and the way in which I experienced an event. This ongoing hermeneutic cycle has forced me to continually re-
examine my beliefs and my prejudices and constantly reinterpret the meaning of the data I had collected.

Gadamer (1975) stated that we run the risk of changing or transforming who we are because of our experiences. We have a choice of how we react to these experiences, but we are always changing and evolving in the process. I myself have changed much in the last 14 years. Much of this change is a direct result of the process of working towards the completion of my Ph.D. As I read an ever-increasing amount of literature related to my dissertation and discussed the topic with my fellow participants, I was forced to re-evaluate all my prior preconceptions and prejudices about SCI and what the experience of SCI meant to me. My experience of SCI was ongoing and ontological. I realized that there would never be a conclusion or a finishing point, from which I could write objectively, from which I could write from the position of an all-knowing, transcendental self.

The methodology consists of the participants sharing their life histories using stories and narrative to understand the experience of the trauma of spinal cord injury. Phenomenology and hermeneutics are the tools used in an attempt to understand the essence of the participants' lived experience and to ascertain which bits of data are fecund and how those bits are linked together. The lived experiences of the participants and their interpretation have been used to open up the literature review. The methodology is an intense conversation between these parts. My task in this process is to become involved in this conversation and to act as a conduit and a filter so that each part can be read in relation to the other parts. At the end of this process it is hoped that the topic of what happens in the mind of a person when he experiences a SCI will be better
understood. Now I will turn to consider the narrative, phenomenology and hermeneutic aspects of this research.

**Narrative**

My own personal experience and lived reality has driven me for 14 years to try and come to an understanding of what has happened to me as a person because of the trauma of a split-second chance occurrence. I am at once the same person who slid headfirst into home base and yet I am radically different. What happened to me, to my mind, spirit, and being--to my consciousness?

The experience of SCI is one of total world collapse. It is a descent into emptiness, despair and nothingness where the external factors that contributed to a person's identity and self-image are stripped away from him or her in an instant.

Yet many people who experience SCI manage to overcome the physical, psychosocial and environmental barriers imposed upon them and lead full and productive lives. What happens inside these people that separates them from others who experience SCI and remain in the grasp of world collapse, nihilism, despair, depression, and the projection of blame? The question arises, how would one be able to understand what happens inside the mind of a person who experiences the trauma of SCI?

Narrative is a way to make sense of previous experiences. Ricoeur (1974) pointed out that narrative is a conceptualisation of experiencing and knowing as it is connected with being and doing in human temporal existence. In order to understand an experience, humans need to be able to reduce things to objects in time and space (Cochran, 1986). Time real, or imagined, becomes human when narrative is articulated (Ricoeur, 1974). Ricoeur (1974) maintained that humans transform human experience into language with
the use of signs and symbols. These signs and symbols are used to create language that is
then used to create stories with a beginning, a now and a future. This is necessary because
we cannot sense time; therefore we must process time in the human consciousness by
processing experiences into stories (Cochran, 1986). To put events and experiences into
stories causes a person to use skill, judgement, and application to make meaning out of
experiences. This self-knowledge is never to be completed and can only be found when
articulated (Polkinghorne, 1988).

We live in a story. When a human being performs a task or is involved in an
experience, it is processed and reflected upon. From this cognition or temporal
organisation, we organise events into stories (Carr, 1986; Crites, 1986). We represent life
as a story. Hardy (1968) observed that, “We dream in narrative, daydream in narrative,
remember, anticipate, despair, believe, doubt, plan, revise, criticise, construct, learn, hate,
and love by narrative” (p. 51). Narrative is the primary act of the mind that makes
patterns that connect (Bateson, 1979). Bruner (1986) added that it is a mode of cognitive
functioning to process information into narrative.

Stories are used to explain why things change from beginning to end (Danto,
1985). A story is a material way of understanding and making sense of interactions
regardless of how diverse, discrepant, or abstract the parts may be. This requires
judgement and makes them understandable (Mink, 1978).

Other researchers, including Sullivan (1984), Harré, Clarke, & Carlo (1985), and
Mandler (1984) agree that stories are a meaningful way of organising human actions into
meaningful sequences of events. In fact, it appears that only through the ability of stories
to connect parts into a whole can an integrated account of an experience or an event be generated. Cochran (1988) stated:

Although psychology has tried to operate with a narrow version of efficient causality activators, controlling stimuli, the inadequacy of this mechanistic focus seems to be generally recognised but the problem of fragmented types of explanation has not been faced. That is, if we use different types of explanation, we must find some way to make them cohere into an integrated account. Narrative appears to be the only structure that seems capable of such integration, and it does so with such ease and naturalness that understanding can be virtually equated with a complete story. (p. 8)

The life stories of participants who have experienced SCI offer us an integrated account of this quest for healing and wholeness. I do not want to focus on isolated instances and use statistics to quantify each instance. I do not want to focus on the personal idiosyncrasies of each life history. Instead I will use phenomenology and hermeneutics to explore what the stories have to say about the topic of my research, which is to understand the experience of the trauma of SCI.

Phenomenology

Phenomenology is important to this research because by definition it grounds the research in the lived experience, the lifeworld of human beings. Phenomenology requires the use of signs or symbols in the form of written or spoken text because it is through this process of writing or narrative that a person’s experiences are brought to consciousness (Ricouer, 1984; Van Manen, 1984). Sartre (1970) observed, “consciousness and the world are given at one stroke essentially external to consciousness the world is nevertheless relative to consciousness” (p. 54). Sartre (1970) also observed, “phenomenology reveals a consciousness which ‘bursts outward’ a consciousness which is nothing if not a relation to the world” (p. 54). Bertrano, Husserl’s student, made the observation that “consciousness is always conscious of something” (Lyotard, 1991, p.
Osborne (1990) stressed that consciousness always has an object and that consciousness is an intentional act directed at a specific object. Intentionality is a process in which consciousness becomes aware of a specific object. In the writing of an experience, I become aware of a particular instance that has meaning for me. I, as a subject, want to understand the essence or meaning of a particular experience. I then use the phenomenological reduction, which is not introspective but a retrospective reflection of a lived experience in the real world, to understand that experience (Van Manen, 1990). This reflection is an intentional act that is brought to consciousness by reliving a particular experience that is brought to life through writing or retelling the story. This intentional act of retelling an experience is an attempt to understand the essence of a lived experience. Merleau-Ponty (1962) defined phenomenology as the study of the essence of the lived experience of the work and, accordingly, treatment of every problem is an attempt to define an essence of perception or an essence of consciousness. Van Manen (1990) explains, “the essence or nature of an experience has been adequately described in language if the description reawakens or shows us the lived quality and significance of the experience in a fuller or deeper meaning” (p. 10). Husserl (1970) defined phenomenology as the ontological study of being or essence. The essence is only that in which the “thing itself” is revealed to me in an imaginary giveness (not metaphysical or platonic) (Lyotard, 1991, p. 40).

Van Manen (1990) defines phenomenology as a pure description of lived experience. This lived experience is in the real world. Pure description means that we view the world and understand our experiences without preconceptions and presupposition by regarding the phenomenon innocently, and have a childlike openness.
to the experience (Sadler, 1969). This process of placing one’s preconceptions and knowledge of a phenomenon aside and looking to the experience itself was called “bracketing” by Husserl (1970). Husserl (1970) observed, “It is better to make explicit our understandings, beliefs, biases, assumptions, presuppositions and theories. We try to come to terms with assumptions not in order to forget them again, but to deliberately hold them at bay and even to turn this knowledge against itself, as it were thereby exposing its shallow or concealing character” (p. 47).

Removing one’s own preconceptions and prejudices and temporarily setting them aside creates a situation where we become the transcendental subject (Husserl, 1970). We attempt to experience the phenomenon in a pure, childlike and innocent way. Bateson (1979) called this process “disciplined subjectivity.” Gadamer (1975) stated: “We search for the future through dialogue with what is past. We do not recall events that are over. Rather our experiences live in us making us what we are” (p. 60). In other words “we become our experiences.” Van Manen (1986) notes that in every phenomenological research project we don’t simply raise a question that we could drop or change but that we “live it,” that we “become” this question. To truly question something is to interrogate something from the heart of existence, from the centre of our being (Van Manen, 1990).

This presents the very paradoxical nature of phenomenology. Phenomenological research begins in the lifeworld. This is the world of the natural attitude of everyday life that Husserl described as original, pre-reflective, and pre-theoretical (Van Manen, 1990). However, these experiences can only become aware to consciousness when a person removes oneself from the experience and recollects or remembers the experience by
writing it or by telling the story. Putting the experience in writing or into a story, brings meaning and understanding to the experience. However, our appreciation of the meaning and the understanding that our consciousness has of the experience is always something past that can never be grasped in its fullness and depth since lived experience embraces the totality of life (Van Manen, 1986). We choose what to remember and we also choose the meaning to attach to our lived experiences. This is the concept of intentionality. We intentionally choose the object of our curiosity and by a phenomenal reduction attempt to explicate the essence of this experience. To bring this experience to consciousness, I must remove myself from the world to reflect on my lifeworld.

If the phenomenological process is executed properly, this lifeworld can be brought to life more intensely through intentionality because I choose only certain essences to explore. However, once the concept of a text or a story comes to light, then everyone becomes a reader and an author and the question arises as to who is reading whose interpretation as the correct one and what is the true meaning of an experience (Van Manen, 1990). In order to find the true meaning or interpretation of an experience that has used a symbolic form or text to put it into a story, we must turn to hermeneutics.

Hermeneutic Variation to Phenomenology

This research embraces phenomenological hermeneutics. In Husserlian Phenomenology there is a dichotomy: A subject and an object. There is a paradox of meaning and intentionality. The question arises, “Does the intentionality of the subject confer meaning on a text or is the meaning simply built into the text so that the reader submits to it (Maglolia, 1997, p. 61)?” In the Husserlian Phenomenology, the transcendental subject could bracket their prejudices and in awareness of themselves,
remove themselves and become the source of all knowledge. The transcendental subject could then come to a univocal understanding of the author's intended meaning of a text. Ricouer (1984) pointed out that self-knowledge is seen to be construed through the mediation of signs, symbols and texts. Ricouer (1984) did not agree with the concept of a transparent self because "Hermeneutic philosophy gives up the dream of a total mediation at the end of which reflection would once again amount to intellectual intuition in the transparency to itself of an absolute subject" (p. 194).

Heidegger conceptualised phenomenology differently than did Husserl. Phenomenology, to Heidegger, was derived from the combination of two Greek words: "phainomenon" which when translated means "phenomenon" and "legeim" which means, "to let something be seen" or "to uncover" (Magliolia, 1977, p. 62). Heidegger (1962) maintained that the meaning of a phenomenological description as a method lies in interpretation. Interpretation, in turn, is a heurmeneutical activity made necessary because the meaning of a phenomenon does not always manifest itself immediately. Heidegger (1962) did not ascribe to the concept of the dichotomy of the subject-object relationship. Instead he maintained that the "meaning of 'being' is made known to Dasein's understanding of Being by a process of hermeneutical phenomenology" (p. 37). The process of hermeneutical phenomenology is ontological and gives insight into being or "Wesenblick." Heidegger did not see a separation of subject and object in the "Lebenswelt" or lifeworld but an ongoing epistemology of natural implication between interpreter and interpreted. Heidegger (1962) stated in his critique of presence that we need to be suspicious of what presents itself, that we need to see the essence of being and/or beings correctly and in the context of their experience of their lifeworld. Magliolia
(1977) pointed out that Heidegger’s concept of Being-in-the-world is similar to a concept developed by Ludwig Binswanger called “Koinonica” (p. 58). This is a type of consciousness or an experiential circle where selfhood and the outside person or things are participants in the same unified ontological field (Magliolia, 1977). With Koinonica, a person does not dichotomize consciousness into subject and object but experiences “Wettbild” or world design (Magliolia 1977, p. 97). This is similar to the Heidegger’s Being-in-the-world where there is an effortless circling in the lifeworld between the person and the outside without subject or object (Heidegger, 1962). Truth for Heidegger is not verities or a correspondence of subject and object but althea, the “unconcealment of Being” (Magliolia, 1977, p. 68). Althea or the unconcealment of Being, occurs in the lifeworld of the participants and is promoted by the research process. With each interview or article read, the researcher’s understanding about the experience of SCI is expanded, opening the door for a different and new interpretation of exactly what this experience means.

This unconcealment of Being can only be understood when the person expresses his experiences in the form of language, using signs, symbols and text. Language is an extension and expression of a person’s interaction between self and the world. The writing of the text or the telling of a story is an intentional act. Intentionality is by its very nature unique to the lifeworld of the individual speaker because each person relates to his or her lifeworld in a different and unique way. In the creation of the text, the intentionality of the author, because of the specific use of language unique to them, is embodied in the text.
Magliolia (1977) states that language not only embodies intentionally but that language is an extension of the author's intentional field. Heidegger theorised that the author acts as a conduit that receives being and delivers it to the written word. Once the literary text is completed, the author then effectively disappears (Magliolia, 1977, p. 73).

Heidegger (1962) maintained that once there is a text, the hermeneutic process is a projection of "Dasein" (the individual’s existence) towards the possibilities of the text. Significantly, these possibilities as disclosed, exert their own counterthrust upon Daseins. This counterthrust ensures mutual implication of interpreter and literary work so that both belong to the same ontological field (sec 32, p. 188).

Heidegger (1962) observed that understanding was pre-reflective and based on a person’s fore-structure of knowledge based on experience in the world. To interpret the meaning of the text, one had to do a phenomenological description of understanding (sec 32). This means that meaning is neither in the intending act of the reader nor in the literary text. Heidegger (1962) further states, “meaning is precisely the engagement of subject and object and the engagement is a unified As-structure. The As-structure furthermore is performative--it arises when the reader and text participate in a joint act” (p. 197).

This As-structure creates an ongoing conversation between the reader and the text that attempts to create a “restoring of life to its original difficulty” (Caputo, 1987, p. 1). Jardine (1992) adds that this conversation yields “a sense of life in which there is always something left to say with all the difficulty, risk and ambiguity that such generativity entails” (p. 119). This ongoing conversation between author and text refines and corrects the signs and symbols to keep them readable, in focus, and alive so that the object with
all its possibilities remains fluid (Gadamer, 1989). The author (self) and the text (work to be interpreted) belong to the same ontological field. Jardine (1992) points out “at no time is the researcher or the participants outside of the process of emerging self-knowledge. It is an ongoing all consuming process - never ending - because we are already and always emerged in our lifeworld” (p. 119).

Gadamer (1989) observed that the starting point for the hermeneutic process was prejudice. Heidegger (1962) called this a fore-structure or foreknowledge that individuals developed from their being-in-the-world. This fore-structure is alive within us before we encounter something new within our ontological field. The fore-structure meshes with the text or new experience before the interpreter is aware that this is the case (Heidegger, 1962). These pre-reflexive ideas cause the interpreter to arrive at an innocent and naive understanding before he or she consciously know it. This is the first part of the Hermeneutic Circle.

Gadamer (1989) pointed out that meaning is the phenomenological description of understanding and that when we interpreted the meaning of something we actually interpret an interpretation (p. 26). Heidegger (1962) stated:

Meaning is that wherein the intelligibility of something maintains itself. That which can be articulated in a disclosure by which we understand we call ‘meaning’. The concept of meaning embraces the formal existential framework of what necessarily belongs to that which an understanding interpretation articulates. (p. 193)

Parker (1985) pointed out that the dialogical nature of Hermeneutics means our understanding becomes refined and corrected by the work of interpretation leading to an increased understanding and a more complete interpretive account. Hermeneutics pulls
back the layers of meaning until the core of the experience is exposed. Rowan and Reason (1981) pointed out:

Hermeneutic Interpretation involves a spiral path to understanding increasingly moving to deeper levels of meaning as it encompasses relationships between whole and part, between what is known and what is unknown, between the phenomenon itself and its wider context between the known and what is known. (p. 134)

An important aspect of meaning is context. Without knowing who wrote the text, when it was written, and in which country it was written the meaning of the text could be estranged and different than if this information was forthcoming. Smith (1991) observed that a key aspect of Gadamer’s work is to show the historic-temporal quality of human experience. Because, it is from this position of prejudice, pre-judgement, or fore-knowledge of the contextual nature of an experience, that allows a person a better opportunity at a valid interpretation of an experience.

Therefore, it is critical that the interpreter (in this case myself) understands that the participant’s experience of the world is altered in the physical and psychosocial realm because of his spinal cord injury. In fact, I cannot and in no way can I separate myself from the lifeworld of the participants because I have been Spinal Cord Injured for 14 years. I am the implicated observer and cannot separate myself from the experience of spinal cord injury. However, in order to become involved in the conversation and keep the hermeneutic circle moist and alive, it will be necessary to remain open to the stories, new shared experiences, understandings and realities of the other participants in this research. If for a moment I believe that “I” understand the meaning of the experience of being spinal cord injured, then I will close down the conversation and there will be little of opening up to new shared realities.
Van Manen (1990), when writing about quantitative research, pointed out that the researcher should “live” the research and “become” the research. I have no choice but “to live it” and “be it” because I already am and always will be a spinal cord injured male. This makes it impossible to be objective because the position from which my reality, my tradition, and my cultural context are formed is prejudiced because of my experience of SCI over the last 14 years. It is from this position of prejudice that my hermeneutic circle of understanding starts. Jardine (1992) reminds us that, although we start with tradition and from a position of prejudice, “in the mist of such potentially dusty and deadened talk, new life interrupts causing a rupture right in the middle of things” (p. 120). Thus, it is possible for me to be totally immersed in the research, having prejudices and preconceptions, yet the literature and the stories of the participants have generated new insights, understandings, and interpretations to further my knowledge of the experience of the trauma of SCI.

Without fore-structure, prejudice, or pre-conception, Heidegger (1962) argues that interpretation of any kind is impossible, because it is from this position that one starts their interpretive process and interaction with the text. The author, in our case, the participants, significantly disappears and the text stands on its own. The meaning intended by the author is found within the text as an As-which or aspect which reveals the reality or the Being-in-the-world of the author (Heidegger, 1962). The interpreter, or in this case, myself, is never neutral and approaches the text with an implicit or explicit question known as an As-question (Heidegger, 1962). The nature of the As-question and the As-which interacts with mutual intentionally to create an As-structure that will determine the interpretation and the meaning derived. Heidegger (1962) points out that
this process can generate a multiplicity of interpretations, interpretations that may conflict, or interpretations that are not consistent with the intention of the original author. Heidegger (1962) is emphatic that conflicting interpretations can be equally valid because life and the real world are like that. It is hoped that the data bits, aspects, or dimensions that I select, and the interpretation of these bits of information, accurately reflect the participants’ experience of spinal cord injury. These interpretations should be aided by the fact that I am spinal cord injured and share the same contextual environment. However, this does not rule out the possibility of conflicting understandings and interpretations.

In summary, phenomenological hermeneutics is ontological. It must incorporate an epistemology of mutual implication between interpreter and interpreted. Second, it must see “the essence” as being correct. Third, it assumes that there may be multiple and contradictory interpretations that can be simultaneously valid. Fourth, it assumes that our preconceptions and prejudgements act as a starting point for understanding. This research is about Being-in-the-world. It is about the experience of being a male with a spinal cord injury living in Calgary in the 1990s. Heidegger (1962) established that hermeneutics is the fundamental practice of being itself. “The phenomenology of being (Dasien) is a hermeneutic in the primordial significance of this world where it designates the business of interpreting” (p. 65). Thus, understanding the life of a spinal cord injured male after his accident, which is being looked at in this research, is an interpretive act and can best be understood by using a phenomenological/hermeneutic approach.
Fecundity of the Individual Case

This research is not a statistical quantitative analysis of spinal cord injured males. It consists of the phenomenological/hermeneutic interpretation of the life stories of six men who experienced spinal cord injuries. It is through the lived experience of these men that I am trying to understand the experience of the trauma of SCI. I thought it was important to discover and explore common themes and to attempt to generate a grounded theory. However, it was also necessary to recognise and remember that there may be unique fecund instances in the individual stories that need to be addressed. Gadamer (1989), when writing about the fecundity of the individual case, stated:

The individual case on which judgement works is never simply a case; it is not exhausted by being a particular of a universal law or concept. Rather, it is always an “individual case” and it is significant that we call it a special case because the rule does not comprehend it. Every judgement about something intended in its concrete individuality (e.g., the judgement required in a situation that calls for action) is strictly speaking, a judgement about a special case. That means nothing less than that judging the case involves not merely applying the universal principle according to which it is judged, but co-determining, supplementing, and correcting that principle. (p. 39)

Several times during the interviews a particular moment or statement would strike me with such power that it triggered a response deep within me at some primitive primordial level. The statement would address me at gut level and rip open a fissure of never before examined understandings revealing new facets of a topic and forcing a new ambiguity of meaning. Several times during my interviews there were fecund and evocative instances which created an “ah ha” experience and created an automatic expansion of understanding. These instances addressed me with such power and in such a manner that I had to speak to them and include them in the conversation even though the statement was only mentioned by one of the participants. Gadamer (1989) observed that
understanding begins when something addresses us (p. 299). In this research there are certain instances that called for my attention and created new understandings about spinal cord injuries and counselling. It is not usual to include information from the research in the Methods section but I would like to demonstrate the power that the fecundity of one statement can have on a research project and on a researcher. Most participants stated that a person with a SCI must accept their condition or make the necessary accommodations before healing can occur. However, one participant stated, “denial is not a bad thing especially at first.” This participant stressed how the removal of the hope of recovery to some would be more detrimental to their recovery than temporarily holding on to a false dream. This statement had a tremendous impact on me because the doctors and nurses kept telling me for the first three months that I would not walk or move again and that I should accept this as soon as I could and get on with it. Today I live independently and can walk with forearm crutches. They assumed I was in denial. I never gave up hope that I would walk again.

In fact, I believed I would walk again. This helped me work harder in therapy and maintain a better attitude than many of my peers because I sincerely believed I would get better if I worked hard. It was my hope and faith that sustained me in my limited recovery. If I had not recovered, then my “denial” would have sustained my exertion and effort, if only for a short time. I still believe I have a chance to walk again without the use of crutches. I also know that I must be realistic about my abilities in the here and now and make the appropriate accommodations to live as full a life as possible. This one statement about denial not necessarily being bad opened up the whole issue of the paradoxical relationship between denial and acceptance and the impact that it could have on hope and
recovery and the far-reaching implications this concept may have in rehabilitation counseling. This research is not about statistics or averaging scores. The fecundity of the individual case or statement is important to increase the understanding of the trauma of SCI.

The Conferring of Validity

In applied science, quantitative research methodology is used which demands reliability, validity, generalisability, and replicability. These items are difficult to prove in qualitative research. However, techniques have been developed which when present demonstrate validity. This study used narrative or the stories of the spinal cord injured males so the reader can come to a better understanding of the participant’s lived experience. These stories however, may not necessarily reflect “true” reality but they reflect and illuminate the “lived” reality as perceived and remembered by the participants (Polkinghorne, 1968).

I used hermeneutic interpretations of these stories in an attempt to find the meaning of these experiences or phenomena. I also used a second, and in some instances a third, interview as recommended by Osborne (1990), to make perception checks with the participants to make certain that I understood what they meant in their stories. At no time can I guarantee that this research will be valid in advance. I attempted to create a positive relationship with my fellow participants while remaining true to myself. I used myself as an instrument of interpretation and looked to the text for the data while remaining sensitive to the deeper meanings and patterns that were evolving from the research.
In Anthropology Van Manen (1984) believed that appearance and verisimilitude should be looked on as equally important as reliability and validity. Robinson and Hawse (1986) proposed the idea of "authenticity" by examining the economy of selectivity, and the familiarity of the narrative. Heidegger (1962), when speaking of authenticity, stated the following:

To be sure we genuinely take hold of this possibly [primordial knowing] only when, in our interpretation, we have understood, in our first, last and constant task is never to allow our fore-having, fore-sight, and fore-conception to be presented to us by fancies and popular conceptions, but rather to make the scientific theme secure by working out these fore-structures in terms of the things themselves. (p. 195)

Van Manen (1990) speaks of this process as being the validating circle in qualitative research. It proceeds as follows: A good phenomenological description is collected by lived experience and recollects lived experience--is validated by lived experience and it validates lived experience.

If the hermeneutic process is successful, then the authenticity, appearance, verisimilitude and fidelity of the experience of the participants will be maintained, exposed, and made available to the sensibilities of the reader. Young and Collin (1988) described how there is a built-in standard of common sense in Hermeneutics and that the reader conferred validity to the research more than the researcher can lay claim to having created it. Hopefully, the interpretation of the participants' stories will resonate with the experience of other people who have experienced a spinal cord injury. However, it is only through the public sharing of this research that the "validity" of the research can be determined. In the end, the readers themselves will adjudicate the validity of the research by determining if the themes presented and the grounded theory generated implicate
them, in a strong and powerful way, and illuminate the meaning of the participants lived experience with the trauma of SCI. In qualitative research validity cannot be guaranteed. It is hoped that the phenomenological/hermeneutic approach used in this research is of such high standard that the authenticity, appearance, verisimilitude, and fidelity of the participants’ stories will be interpreted in such a manner that the audience will confer validity on this research.

In conclusion, to this approach to research section, I will draw attention to the fact that, although there are strong narrative and phenomenological components to this research, it is at its heart, hermeneutical.

Research Procedure

Selection of Participants

The subjects involved in this study are referred to as participants. This study is collaborative in nature and is designed to have the researcher and the participants work together to explore the experience of recovery from a spinal cord injury. I decided to advertise for volunteers to participate in my study (see Appendix A) at the following locations:

a) University of Calgary
   i) Education Building
   ii) Library
   iii) MacEwan Hall
   iv) Physical Education Building
   v) Medical Centre

b) Southern Alberta Institute of Technology

c) Mount Royal College

d) Bow Valley Hospital
i) Spinal Cord Clinic
ii) Physiotherapy
iii) All bulletin boards
iv) Gymnasium
e) Canadian Paraplegic Association
f) Handiwheels - wheelchair repair
g) Eau Claire Physiotherapy
h) Copies were given to students at the University in Education who stated that they knew someone who might be interested in the study.

I listed the volunteers in the order that they responded and had a meeting with each person who had volunteered.

The participants for this study were selected using the following criteria:

1. The first 10 qualified male participants (those who met all the criteria for participation) would be included in the study. Male subjects would be used because approximately 80% of spinal cord injured people are male (Canadian Paraplegic Association, 1992; Trieschmann, 1988). I did not include female subjects in this study because the results could be confounded and skewed because of gender issues.

2. Each participant was to be a minimum of five years post-injury. This arbitrary time period came from discussion with several doctors and rehabilitation nurses. The consensus of opinion was that it took a minimum of one year for paraplegics to recover and quadriplegics a minimum of two years to recover while some spinal cord injured never adapt or adjust to their new situation.
3. Participants were to be verbally fluent with an ability to communicate thoughts, feelings, and perceptions. I wanted to make certain each participant was capable of telling his story and answering complicated questions. The participants needed to be able to discuss their experiences in depth. Therefore, verbal fluency and a good memory for details were important selection criteria.

4. Participants needed to be willing to be involved in the study. The participants were told in advance that it would require 5-6 hours of their time and at least two interviews. Each participant had to be willing to sacrifice the time and energy to make the study successful.

5. Participants needed to have a self-perception of successful adjustment to spinal cord injury.

I was interested in finding out what happened in the mind of a person when he experienced the trauma of a spinal cord injury and how he successfully adjusted and coped with SCI. The literature on rehabilitation demonstrates that there is a high correlation between self-rating scales and objective testing of such things as depression, adjustment, satisfaction and good health. Therefore, critical to this research, it was necessary that each participant had a strong self-perception that he had successfully made a positive adjustment to his spinal cord injury.

Eight people contacted me to be participants in my research. I made an appointment with each of them for an initial interview to ascertain if, in fact, each candidate fulfilled the criteria for participation in the study. In this initial interview I explained what the research was about, the participant time commitment, and what our
roles would be. I also encouraged each prospective participant to be candid and ask any questions he wanted. Five of the candidates met all of the criteria. I made appointments with each of the five volunteers, who now became full participants, and proceeded to meet with each of them for the first round of interviews.

**Negotiated Roles**

The participants were encouraged to think of themselves as equal partners in the research. A non-hierarchical relationship was encouraged even though the roles of interviewer and interviewee were different. From the original meeting and throughout the research, an attempt was made to develop positive rapport and mutual trust. This was intended to encourage sharing of experiences and to help to make the information rich and authentic. It was important that the participants be given time, space and opportunity to express their voice and to develop an I-Thou relationship (Buber, 1958). This development of a connectedness or empowering relationship can only be developed in an atmosphere where there is a feeling of equality, trust, caring and mutual intent (Hogan, 1988). The participants were encouraged to view themselves as co-researchers (Colaizzi, 1978, Mishler, 1986; Osborne, 1990).

The participants determined the time and location of the interviews. The participants were given copies of their interviews and given the opportunity to edit stories and guarantee that the interpretation of their stories and the themes generated from them were accurate. If at any time, stories or topics became too sensitive, the participant had the option to omit the topic or continue at another time. I was concerned that re-telling the story of his accident and rehabilitation might trigger a psychological reaction in the participant, which he might not be prepared for. Therefore, I received the permission of a
certified psychologist to refer my participants to him free of charge if such a crisis should arise.

**Compliance with Ethical Standards**

Each participant was asked to sign a written consent form (See Appendix B) before I started the interview procedure. He was asked to read the consent form and I explained the implications of each paragraph. Before signing the consent form, I encouraged each participant to ask any questions he might have had and discussed each question until the participant was satisfied that his question had been addressed.

The consent form indicated the following:

a) The aims and methods of the research.

b) Responsibilities and time commitment required during participation in the study.

c) The possibility of publication of the results, which would then become public knowledge.

d) Potential risks and benefits. The participants were advised that there were no risks greater than those encountered in everyday life. They were also advised that they could withdraw at any time and that a certified psychologist would be available should the interviews trigger a negative reaction.

e) Anonymity. The participants were guaranteed anonymity by using pseudonym initials in the transcripts. All tapes, transcripts, memos and research information were to be kept in a separate locked file and destroyed when the research project was completed. Further anonymity was guaranteed by allowing each participant the opportunity to change or delete any information contained in the transcripts that might identify him. Also, to further protect the anonymity of all the people
mentioned in this research, fictitious initial pseudonyms or names were assigned to everyone except for Dr. Blaire.

**Data Collection**

The original plan was to use semi-structured interviews. Each participant would tell about his life before the accident, next he would describe the accident, and then he would describe his rehabilitation. Finally, he would describe his present life and the impact that the SCI had on his life. I created a list of questions or an interview guide for my first interviews. I had generated several themes that I thought were pertinent to understanding the experience of SCI. The interview guide I developed was designed to address these themes. The procedure seemed straightforward. Each participant would answer every question and then I simply needed to correlate all the answers and I would have the necessary information.

During the first interview something seemed wrong. I was controlling things by the questions I was asking. My agenda was being served and not the participants'. This reminded me of the rape model of research talked about by Oliver (1989). It seemed that the interview was stale and dead. The participant and I seemed to talk about topics and not his experiences of SCI. I was disappointed with the first interview and didn’t know quite what to do.

One week later a fellow graduate student asked if I would assist him in completing an assignment for a course on career development for people with disabilities. I agreed to help. The assignment was to undertake a career assessment on a volunteer. He conducted an unstructured interview, where he had me tell my story. I was to include my youth, work experience, school, and relationships. He kept a time line and asked a few
questions but basically I told a continuous story that took over three hours. On finished the interview, I asked him for a typed copy of the transcription. As I read it, I was surprised that the important issues about spinal cord injury had been addressed in great detail even though this was supposedly an interview about career development. The transcript was so intense and personal that I decided to use the transcript in the research and become a full participant in the study.

It changed my interviewing strategy because, while I was being interviewed, I relived all the emotions of my accident. I was free to tell my story the way I wanted to. I could spend time and discuss the themes and issues that were salient to me. I needed to give the participants the freedom to choose the stories they wanted to tell and to tell them the way they wanted to. This would allow my research to be more powerful and have more fidelity and authenticity because it would allow the participants to give a richer "thick description" of their experiences that were important to them and not simply what experiences I thought were important.

I didn't realise how empowering research could be until I allowed the subjects to simply tell their story unencumbered. Van Manen (1990) also said:

Certain openness is required in human science research that allows for choosing directions and exploring techniques, procedures and sources that are not always foreseeable at the outset of a research project. (p. 162)

Gadamer (1975) pointed out that when using phenomenology and hermeneutics there is no one pre-set method. I adopted a new interview procedure from Cochran's (1985, 1986) dramaturgical method for the eliciting of participants' stories. I would have the participants give an account of their journey to wholeness by telling me a story with a
beginning, middle, and end. The beginning would be his life before the accident. The middle would be the accident and the rehabilitation. The end would be the present time.

In order to facilitate the participants’ telling of their stories, I used a humanistic approach as outlined by Rogers (1961). This meant that I used unconditional personal regard for each participant and employed empathic listening and paraphrasing to help him tell his stories. I developed an intimate relationship with each participant where each participant felt safe and respected and that his story was being listened to. Buber (1958) recommended developing an I-Thou relationship with the participants and Collin and Young (1988) recommended a close relationship for hermeneutic inquiry. I realised that I had to be able to trust myself as an instrument to listen closely and ask the proper questions and trust my judgement and experience (Mair, 1989). I also had to be able to listen without being judgmental about any of my fellow participant’s stories because it would shut down the process if I reacted negatively. When one of the participants took the risk to talk about how he was addicted to drugs and sex, being non-judgmental freed him to talk openly about the whole issue of sexuality and drugs in the disabled world without holding back.

Each interview typically took between 3 and 4 hours and when transcribed was approximately 50 single-spaced typewritten pages. After each interview the transcription was analysed for thematic aspects (Van Manen, 1990) and those aspects that were found were those that resonated with the stories of the other participants and with my own lived experience. The unedited transcripts from their interviews were returned to each participant to ensure accuracy and to see if any additional themes would be generated in the re-reading. I included the common themes I had identified in all the interviews along
with specific themes that they had identified in their interview with me. The participants were asked to think about the themes and read the transcript in preparation for the second round of interviews. I collected all edits and corrections from the participants and encouraged them to keep a corrected copy for their journals or personal histories.

A second interview was held with each participant and typically took between one and two hours in length and was approximately 25 single-spaced typewritten pages in length when transcribed. During the second interview, I discussed the common themes and those themes that were specific to that participant in great detail. We shared our perceptions of the themes and how they were connected. We also discussed why some themes appeared in their life and not in the lives of some of the other participants.

The second interview was used to discuss the emerging themes and the literature on SCI with each of the participants and to get their opinions on my interpretations, not only of what they had said but about all aspects of the research. I found that by including each participant in the theorising and synthesising of the literature, we further strengthened the I-Thou relationship developed in the first round.

In my original proposal I was to interview ten participants. However, only five volunteers were acceptable. I also made the decision to include myself as a participant observer. The first round of interviews generated approximately 200 single-spaced pages of transcripts while the second round generated approximately 100 pages. The data generated from these interviews was of such high quality in terms of richness, and of thick description that it was considered unnecessary to include more participants.
Interpretive Analysis

Consistent with qualitative research designs, the data analysis took form as an ongoing, recursive dialog between the data and myself. The interpretive process was initiated as I attempted to understand my own experience of SCI. This process of attempting to understand my experience of SCI formulated my prejudices or my position of fore-understanding (Addison, 1989; Osborne, 1994) from which I entered into the "hermeneutic circle" of inquiry. I did not attempt to "bracket" my preconceptions or prejudices and completely immersed myself into the lifeworld of the participants. I did not realise at the outset the transformative effect and the deep impact conducting the research would have on me. Van Manen (1990) commented on this phenomenon when he said:

Phenomenological projects often have a transformative effect on the researcher him or herself. Indeed phenomenological research is often itself a form of deep learning, leading to a transformation of consciousness, heightened perceptiveness, and increased thoughtfulness and tact. (p. 63)

The methods of analysis for grounded theory as outlined by Glaser (1978), Lincoln and Guba (1985) were not used because the predetermined operational procedures, including "open coding" and "integration," tend to have researchers looking for data rather than at data leading to emerging theory (Schatzman, 1991). This tends to divert attention away from the data and focuses the attention toward the operational steps prescribed by the procedure (Glaser, 1992; Schatzman, 1991). Grounded theory as proposed by Lincoln and Guba (1985) may have constrained the data and misrepresented the phenomenon I wanted to understand (Eisner, 1997). In fact, Glaser (1992) stated, "what the Strauss and Corbin method produces is ‘forced, full conceptual description’ but not grounded theory" (p. 5).
I used “dimensional analysis,” as outlined by Schatzman (1986, 1991) to develop this grounded theory. Schatzman proposed that dimensional analysis is an extension of the natural analytic process and is distinguishable from everyday analysis by the recognition and consideration of greater numbers and kinds of attributes with any given situation (Robrect, 1995). Schatzman (1991) views analysis as an intrinsic process of thinking learned early in social life along with language that was put into practice whenever an experience is problematic and action is required. Thinking is also understood to be governed by the reflective of one’s interaction with the data (Schatzman, 1991).

Dimensional analysis uses the same logic a person would use to analyse a story. A good story explains the relationship among things and events. A story provides a context in which actions and processes occur under certain conditions that create consequences and implications (Schatzman, 1991). When we listen to a story, we consider attributes and bits of information as they are described (Robrect, 1995). We consider actions taken in relation to the context, conditions and consequences (Robrect, 1995). If any part of a story demonstrates inconsistencies or presents problems in understanding or credibility we ask questions (Robrect, 1995). The dimensions of a story that provide the greatest explanation for the relationship among dimensions are selected as the central or key perspective from which to organise or choreograph the data (Schatzman, 1991).

Grounded theory is that “which gives theoretical and explanatory form to a story that would otherwise be regarded at best as a fine description” (Schatzman, 1991, p. 313).

I proceeded to analyse the interview data in a naturalistic way in an attempt to identify, assemble, and pattern the data into a coherent model that would explain the
"whole" of "it" or "what is all going on here" (Schatzman, 1991). I continued to reread the transcripts and selected themes, aspects, or dimensions that appeared to be salient to understanding the phenomenon of understanding the trauma of SCI. Once I had identified a theme, aspect, or dimension, I would immerse myself in the literature to see how that part fit with other parts and how everything fit into the whole.

The process of "early analysis" is concerned with the finding of information, logistics, and identifying all salient dimensions of the phenomenon without consideration of the relative importance, relationship, or meaning of the specific concepts (Schatzman, 1991). It has also been seen as a creative process (Oiler-Boyd & Munhall, 1993), not a rule-bound activity, but a free act of "seeing" meaning (Van Manen, 1990) that has no single tried-and-true method (Wiess, 1994).

Over a period of four years I continued this process of identification of data bits and dimensions and placing these dimensions into clusters and naming them. Then, I would place these clusters into categories and attempt to identify the underlying patterns necessary to construct a grounded theory for understanding the trauma of SCI. I found this very frustrating because I sensed that something was missing but I didn’t know what it was. Schatzman (1991) maintained that before a researcher could construct a sufficient explanatory matrix to develop a grounded theory, two things were necessary. First, that the researcher requires a critical mass of considerations before he or she can construct an explanatory matrix. Second, the researcher requires a sufficient knowledge and understanding to assign values to concepts in order to identify and place dimensions into appropriate categories.
In 1997 I had a series of personal setbacks. I had three hernia operations, lost a significant relationship, and experienced some extreme financial difficulties. I was overwhelmed. This experience made me realise that long-term adjustment to SCI wasn’t a linear process. Re-experiencing “World Collapse” shifted my perspective and the way I interpreted the literature and the interviews of the participants. During this period of time I discovered new literature on depression, buffering effect, hope, and despair. The struggle to recover after my operations and the misfortunes I had experienced forced me to mature and grow. This process shifted my perception of long-term adjustment to SCI and allowed me to understand “what was important,” “what was legitimate,” and “what was reasonable” concerning understanding the trauma of SCI (Sarkantokos, 1993). This, in turn, gave me sufficient knowledge and understanding about trauma and SCI to assign values to concepts and categorise dimensions. The new found understanding and the re-analysis of the literature and the data provided me with knowledge sufficient to create a critical mass of dimensions and categorise them into a pattern where what was involved in the phenomenon was revealed (Artinian, 1998).

Schatzman (1991) stated that once the theoretical saturation is realised, the interactive, cumulative, and integrative aspects of the principal operations of this research are performed virtually simultaneously. When I, as an instrument of interpretation, was ready, and when the data collection had reached a critical mass of considerations, I had the pleasant surprise of experiencing this phenomenon.

I was sitting at my desk staring at the blank computer screen trying to write an explanation of my theory of understanding the trauma of SCI. I didn’t seem to be able to know where to start or how to link all the information together to make sense of it all. I
re-read all my summaries and notes and then sat for several hours deep in thought trying to make sense of everything. I took out a clipboard, a pen, and some paper and thought to myself, “There are two main parts to this process, one is world collapse and the other is long-term adjustment.” I started to list different aspects and dimensions without notes or consideration of what to include or which parts to exclude. I had an experience of alethea where everything unfolded and the parts fit into the whole. Time and space fused into an all-embracing experience of satori. In three hours the complete model had been constructed.

I realised at this point that I didn’t need to collect any more data because the scope and the complexity of my topic had been sufficiently appreciated. The process had happened simultaneously. I had taken the different dimensions, clustered them, and then given these clusters names (Schatzman, 1986). Then I used these key perspectives as a catalyst to stimulate categorisation and conceptualisation within the developing theory by directing subsequent logic and inquiry (Schatzman, 1986). The model I created acted as an explanatory matrix in which the grounded theory could develop and emerge. The model provided a framework for the clusters of dimensions to be categorised and patterned into its parts, attributes, interconnections, contexts, conditions, processes, and implications (Schatzman, 1986; 1991).

I simplified and reconfigured the model several times over a period of months, through a process of integration and reintegration, until I arrived at a point of theoretical saturation where the final model provided a meaningful explanation of understanding the trauma of SCI. The theoretical development of this grounded theory can be explained by
dimensional analysis as outlined by Schatzman (1986, 1991), while hermeneutics can explain how this process was operationalised.
CHAPTER FOUR
RESULTS OF INTERPRETIVE ANALYSIS

Introduction of the Participants

In this chapter I address the themes that emerged from the participants' life stories. Schatzman (1986, 1991) referred to the emerging signs, symbols and texts that presented themselves to the researcher, as aspects or dimensions. However, in this chapter, these aspects and dimensions will be presented as themes. While this research does not focus on the pure subjectivity and idiosyncrasy of each of the participants' experience of their SCI, I thought it might prove helpful if a brief preliminary history of each participant is presented. This will allow the reader to have a better understanding about who is making a statement later in this chapter.

The oldest “break” or participant, who had been SCI the longest, broke his neck in a diving accident in the summer of 1977. LN lived in a small town in southern Alberta. He was 18 years old and had just graduated from high school where he had been an outstanding athlete. He was going to marry his high school sweetheart and go to university and become a mechanical or electrical engineer. LN was very independent and enjoyed being alone. He loved to hunt and fish and be outdoors. LN was very good with tools and loved to fix and repair things. He dove into the local swimming hole and broke his neck and became a complete lesion C-5 quadriplegic. LN and his girlfriend broke up shortly after his accident. LN completed a degree in business and was going to become a CA but decided to become a counsellor. He currently lives independently but requires assistance in the morning to get up and dressed. LN drives his own vehicle and is currently not involved in a relationship. LN now works as a counsellor and is a director.
of a government agency. LN uses an electric chair outside the house and uses a manual chair at home.

TB was involved in an automobile accident in the summer of 1981 when he was 29 years old. He was married and had two children. He was a foreman on a large mixed farm and loved the outdoors. They lived in a separate house on the farm. He loved to hunt and ride motorcycles. TB doesn’t remember the accident or much of the first year because of the head injury he received during his accident. His wife left him while he was in the hospital and divorced him soon afterwards. TB is a C-5 complete lesion quadriplegic. He lives alone in his own home in a small town in southern Alberta and drives his own vehicle. TB does his own ADL (aids to daily living) including dressing and preparing meals. He has help come in once every two weeks to clean. TB uses a manual chair all the time and often wheels a mile down town and back. TB takes courses at a college but he does not need to work. He takes pride in taking care of himself and maintaining his house. At the time of this writing he was not involved in a relationship.

BA was 19 in the summer of 1982 when he was involved in a motorcycle accident that left him a T-4 complete paraplegic. He had been a tremendous athlete in high school and was aggressive in sports. He was involved in a serious relationship when the accident occurred but the relationship ended shortly after the accident. BA was a hard worker and had a good job at the airport and had already saved money and owned a motorcycle and a car. After the accident BA entered many marathons winning several races and top ten finishes and setting world records in hand cycling events. BA has a burning desire to be successful. He works at three jobs to make enough money to support his new hobby, drag racing. After sustaining an arm injury, BA was unable to wheel in races any more so he
became the fastest street-legal racer in his area at the drags. BA does all his own mechanical work and tune-ups by crawling up into the engine and working on his car that he races with hand controls. BA lives on his own and uses a manual chair. He is currently living alone and isn’t involved in a relationship.

GG was 30 in the spring of 1983 when he was involved in a hang-gliding accident. He completely shattered three vertebrae in his neck and broke two others. GG was told he was going to die immediately after his accident. They took bones from his leg and rebuilt three vertebrae in a complicated twelve-hour surgery and fused his shoulder blades and now he is a complete C-5 quadriplegic. GG was a carpenter by trade and loved to make models of aeroplanes. GG had a pilot’s license and had a passion for flying gliders and hang-gliding. GG loved the outdoors and enjoyed mountain climbing, ski racing, cross-country ski racing, bike racing and running. He studied meteorology to better understand wind patterns and weather to improve his ability to glide and wanted to achieve world records in gliding. GG lives independently and requires an assistant to get him out of bed each morning but he puts himself to bed each night. He uses a manual chair, wheels every day, and lifts weights three times a week. GG still likes to build model planes and has made a career out of self-improvement and self-care. GG was involved in a relationship when he was injured but currently lives alone and is not involved in a relationship.

JC was 26 in the spring of 1985 and broke his neck during a professional ski race. He was married and had no children, doing a B. Sc. degree, and racing on the pro-am ski circuit. He had a very competitive nature. JC was determined that being a C6-7 incomplete quadriplegic was not going to deter him from accomplishing his goals. JC
completed his Bachelor of Science degree and then went on to obtain a Ph. D. in neurophysiology. He has fathered two children and he and his wife remain happily married. JC is currently working for a large private corporation in the research and development division. JC drives his own vehicle, can walk short distances using a brace on one knee, and sometimes uses a manual wheelchair.

I will be referred to as CS. In June of 1985, CS was 36 when he was involved in a baseball accident where he broke his neck in a collision while sliding head-first into home base. He dislocated his neck and fractured C6 and C7. He was diagnosed as being a full lesion quadriplegic. CS had been an outstanding athlete in high school and had gone through university on basketball scholarships. He loved to hunt, fish, mountain climb, and white water canoe. He taught high school Physical Education and coached basketball, soccer, baseball, and track. In his spare time he ran, lifted weights, golfed, and played racquetball. He was married for 15 years and had four children that he dearly loves. CS’s wife asked for a separation after he was in the hospital for six months and divorced him shortly thereafter. CS started to receive sensation in his toes after several months and by nine months could walk with forearm crutches. CS completed a Masters Degree in Education three years after his release from the hospital and is currently completing his Ph. D. CS lives independently, drives his own vehicle, and coaches the local wheelchair basketball team. CS uses forearm crutches and a manual chair, swims regularly, and is currently not involved in a relationship.

That is a brief history of the six participants. I will now consider the themes that arise out of their stories.
Theme Development By The Participants

Two overarching metathemes, World Collapse and Long-term Adjustment to SCI, provide the context for the presentation of the themes and sub-themes. The participants’ statements are quoted verbatim from the research transcripts with two exceptions: (1) Punctuation has been added both to convey the quality of the participants’ speech and to facilitate ease of reading; and (2) The majority of redundant utterances, such as "uhumm" have been deleted from the statements (Weiss, 1994). Because of the complexity of the grounded theory, the number of themes generated, and the thickness and richness of the statements, only the most fecund statements will be presented with each theme. The themes will be presented in the words of the participants to allow their voice to be expressed. I will make comments and observations about the themes and how they interconnect in the discussion section.

World Collapse

The moment of world collapse for a person with a SCI can best be described by TB when he said:

It is pure hell to wake up in the hospital and find out that your life, as you knew it, no longer exists. It is difficult to face what has happened and hard to see what lies ahead. (TB)

The experience of SCI occurs in a split second with no warning. Life, as it was experienced, changes forever. A man with a SCI initially experiences shock at all levels of his existence. His body no longer functions normally and he loses his connectedness with the world by being placed in a foreign environment. Now he is forced to negotiate time, space, mobility, and relationships differently. The themes associated with "world collapse" are presented in a linear fashion but it must be remembered that the themes,
experienced by the participants, occur simultaneously and often in different sequences for each person with a SCI.

**The Trauma of the Accident**

When each of the participants was telling the story of his accident, I couldn't help noting the increase in the intensity of the emotional level of the interview, not simply for the participant, but for me also. The amazing thing was that the memories were as vivid as if that moment had just occurred. It seemed as if this memory and the emotions attached to it had been permanently etched into memory, frozen in time. When describing his accident BA stated:

I came onto the dike full throttle, just going through the gears and there is a bit of a roadway so you could really accelerate and you had to drop down off it and there is a big huge jump and it would just send you, big time. Anyways I came off it too fast so I was in a crossep—hit the jump rear suspension bottomed out -- sprung—the bike the momentum and I started to do an endo. By the time I landed I did such an endo that I hit and the bike hit me and kinda like just twisted. Squished me in two. Like whoa! So I roll over, come to a stop——dust settles——right away popped my eyes open and OH! OH! I couldn't breath. Aye! Holy fuck! Did I fucking wipe out! Is that wild or what! Trying to figure things out——and at that moment in the air when I hit that jump——Then I passed my buddy I was chasing, I passed him in mid-air. I remember I could see him—fucking right over the top of him and crashed right in front of him. He saw the whole thing poor guy and so anyways I am there, he turns around and comes back——You alright? (BA)

BA hit so hard that his leather pants exploded and left him lying naked from the waist down, exposed on the track. He had shattered three vertebrae, broken eleven ribs, and bruised his heart.

This is a real psychological thing. Remember, how I was telling you I always did what I was told to do and I wasn't a rebellious kind of a kid and stuff like that and I didn't want to cause trouble because you know my mom died when I was nine and I sorta started to get the picture. Don't cause trouble. ---So anyways, my brother Ed—the family is freaking and stuff——and my old man shows up and I see him and Oh fuck! I started apologising to him. I regret this now. What was in my fucking head. It was like I was totally fucked up. It is like you are totally helpless. Those aren't strong enough words I am using but it is like, you are so exposed.
You are helpless. You are so open. I had no other description when I saw him. Fuck, I am sorry, because he never wanted me to ride bikes. He knew me and bikes were no good. Maybe that was part of it, I don’t know. Oh fuck! I felt tremendous guilt at that point. —Anyways the point is—I’m there—I knew what happened to me and I had a pretty good idea and then I started to hate life a little bit and they are really concerned because I didn’t realise just how bad the damage was. (BA)

GG was hang-gliding and it was a very hot day. The landing area was small and surrounded by large trees. The heat was causing air to rise off the landing area making it difficult to land the hang-glider.

Just as I was about to clear the tree I caught the top of it or caught a branch which knocked the handlebar out of my hand. I proceeded to go ahead of the glider with nothing to hold onto. This of course made the glider nose heavy and it immediately climbed slightly, rotated upside down and started into a screaming dive. The glider is designed to pull itself out of this type of configuration. I felt the glider suddenly tug out of the dive. With my weight that far forward it didn’t seem to matter, the glider simply pitched back into the dive and I went headfirst towards the ground. Realising the situation I was in. I didn’t expect to survive what was coming up. My only recourse was to put my hands ahead of me knowing that it was actually futile but I still did it anyway. I guess natural reaction. Suddenly I am at the ground with a tremendous jolt. My first reaction was I thought I was dead but reality came through pretty fast and there I was lying on the ground. (GG)

GG went into shock and had a near death experience. He re-experienced his whole life and found himself rushing towards a white almost bluish light.

I had an enormous feeling of calmness, satisfaction, at peace with everything. It was as if everything made sense. There was no mystery anymore to life. It all seemed plain to me. I felt really good about the whole situation, about everything. (GG)

GG came to and realised he had broken his back and thought he was going to die.

It seemed as almost as if I was in a suspended sort of state, as if time no longer existed. You know I was even aware of the wind blowing around too. (GG)

GG was in this suspended state for over half an hour. During this time he reports the following experience:
I started noticing how blue the sky was, how white the clouds were, everything seemed to be crystal clear and amplified. It was as if I was discovering everything for the first time. It gave me a really good feeling inside, a really beautiful feeling. I was almost overwhelmed by this feeling of all good feelings. At this time I started looking around. I was aware of these mosquitoes coming in for the kill. So there I was lying and they are coming up towards my face and my only means of defence, I remember laughing—not being able to brush the mosquitoes away with my hand—which is a natural reaction. I started blowing them away or trying to blow them away with my breath. This appeared really funny to me. I wasn't thinking about pain or anything at the moment. I was just more or less thinking about the mosquitoes and the blade of grass by my eyes and the way things looked. It was almost as if there was no pain actually and there was a good reason for that. (GG)

As each participant told his story the emotions, felt on the day of their accident, reappeared and were evident, as if no time had passed since the accident. In fact, at this moment, as I write about GG's accident the emotional memory of my accident is triggered. I cannot control a tear coming to my eye as I re-experience the smell of the dirt and the chalk, the feel of the cold earth on my back, and the realisation that I am paralysed for the rest of my life. The memory of the accident and the emotions associated with that memory are inextricably linked and do not appear to diminish with time.

BA's accident demonstrates the crystallising effect that a SCI can have on someone's personality. The accident compounded and intensified the difficulties he had been experiencing in his relationship with his father. This resulted in BA experiencing intense feelings of guilt, shame and anxiety at the time of his accident. BA's accident also demonstrates the concept of "unfinished business" that can occur directly from the accident. BA never talked about the accident again with his brother or father and waited twelve years to make peace with his friend who was at the accident.

My best buddies --- six months ago I was doing everything with weren't coming around. It wasn't until 94 I had a real——we spent all night——got a little drunk and I finally came to peace with Glen. (BA)
This demonstrates the erosion of relationships that can occur after a SCI. BA has still not made peace with his brother or father. It was just last year that my brother apologised to me for not coming to see me more in the hospital. He confided in me that he didn’t like coming to see me because he felt awkward and didn’t know what to say or how to act.

The Hospital Experience

A SCI is a tremendous physical trauma. In order for individuals, who have sustained a SCI, to survive they are initially placed in the intensive care unit of a hospital. Then, once they have stabilised, they are move to a rehabilitation ward usually situated in the hospital. The focus in intensive care and rehabilitation is on the physical, on helping the patients recover as much function and become as independent as possible. The participants pointed out that, although the hospital helped them mend physically, it did little to help them psychologically. In fact, they observed that many aspects about their stay in the hospital had a negative impact on them psychologically. These are:

Spinal Shock

When talking about how he felt the first few days in intensive care GG said:

It was like you wouldn’t shut down or maybe I thought that if I did shutdown I was going to shut down forever. I couldn’t get anything to eat. I couldn’t get anything to drink and I couldn’t have sleep.

The Effects Of The Environment

In the first few hours and days of a SCI little consideration is given to what is happening psychologically to the patient because the primary concern of the medical staff is to stabilise the neck and back and keep the person alive. BA made the following comment about how his psychological needs were met:
They know the physiological aspects and OK the bones healed, the tissues healed, and the scars healed and blah, blah, blah, but they don't deal with the psychological aspects and nobody really did. (BA)

Helplessness And Vulnerability

GG talked about how “horrible” he felt when they put him into intensive care.

They took a syringe and injected it fairly close to my ear. I wasn’t quite clear where the needle went in but anyway, felt like my head was freezing and then came the next horrible sound. They kept my head fairly still. Actually it was in a clamp and to my next awareness was the sound of a drill drilling a hole on each side of my head. Oh my God, I thought at the time. Anyway, they drill and then screw the tongs into my head. ----Before I got into the stryker bed they had to get some tubes down me that went into some machines. So I ended up with tubes up my nose, both nostrils and one on each side of my mouth and some went down into the lungs and was draining it. The other went down into the stomach. So needless to say this was quite horrible too. (GG)

You feel like you have a real loss of control of the environment. You have to get up at a certain time to eat and you gotta work out at certain times—they come in the middle of the night and stick a tube in you. ----next thing you know you are being poked and prodded by whoever, whenever and after a while, holy shit, so I just accepted it. That’s the deal. Oh my dignity is being taken away and this and that. And there is no sense in being a prick and fighting and this and that. It’s going to happen anyway. That’s the way it is. (BA)

Loss Of Freedom

BA stated, “I felt like I had done a crime, I was pulled out of society for six months.” RT stated, “So there I was in this stryker-bed strapped and I really mean strapped, you are bound. You are in bondage really.”

Routinisation And Removal Of Choices

The routines in the hospital used to care for the people with SCI are created for the staff not for the people with SCI.

In a rehab ward there are things far more important than schedules. The economist is going to say, “JC, it is too expensive, it can’t be done.” I am not sure I agree with that. ----I think that it could be done. It would need a whole rethinking of some of the approaches and also it may come across as threatening to some rehab programs. In a way it is just as, “What do you need us for then, if this guy is going
to make all his own decisions then what the Hell do you need a rehab program for.” What I am thinking about is showing, allowing choices right off the bat and getting it going and getting the guy thinking, “Why do I need this?” (JC)

Disembodiment And Feelings Of Being Incomplete

When describing how he felt in intensive care GG made the following comment:

My whole world was from my neck to the top of my head, as that was the area I could see and hear and feel. The rest of my body was in total darkness. Not the darkness of not being able to see but the darkness of not being able to touch or feel or respond anymore. It felt cold. It felt dead. It felt as if there was nothing there any more----I think maybe describing the feeling of being a quad is a picture from Crime of the Century by the Electric Light Orchestra (Album cover) but anyways, the picture consists of a prison window, of a human holding onto the bars and all it was, was this window drifting in space and I thought “wow” does that ever describe how I feel right now. (GG)

Secondary Losses

One of the biggest challenges facing a person with a SCI is secondary losses that occur because of the SCI and compound the already existing physical impairments and increase the psychological stress.

One of the biggest things that you have to think about with an injury such as a SCI is the secondary disabilities that come with them. They may not come immediately but they will come. As I have said, I have broken both legs. I have broken my foot. It’s because the bones in my legs are softer than they would be if I was up and walking around. My elbow and wrists are wearing out because of driving. Secondary disabilities are something that we have to learn to live with and learn to try and reduce. (LN)

The other little gratuities that come along with it, the infection, dysfunctional areas, breakdowns, you name it we got it. Those are the things I find annoying. Not so much the chair. A chair I can live with quite easily. One works hard, you build up your strength, you build up your confidence, you build up your awareness only to be struck down by some infection or a breakdown. You end up spending a month on your back or shoulders or whatever hanging in a hospital bed and everything goes to pot. You are back to scratch. You have to rebuild again. (GG)
Loss Of Relationships

When talking about the loss of his friends, BA stated, “They never tell you why they don’t come to the hospital is because they don’t know how to deal with you.” CS was devastated by the loss of his relationship to his wife and virtually quit working out for the last two months he was in the hospital. He spent several hours a day talking to anyone who would listen to him about his separation:

I was getting to the point of doing all right accepting my chair and then my wife told me she didn’t want me to come home and that put me over the edge. It wasn’t like it was added on, it was something that was multiplied. (CS)

TB’s wife also left him when he had to return to the hospital for the second time for an operation.

When I was in the hospital she left. That’s when I spent another seven months in the hospital. That was mostly due to the fact that she left me right then and I was having a hard time accepting, first of all me. To get out of the hospital and survive I had to accept the chair. Then I had to accept her not being here when I got home and that was seven months of Hell. (TB)

Barriers

When individuals experience SCI there are a wide array of new barriers and obstacles that must be dealt with. The physical environment, in many instances, becomes inaccessible and people with SCI are treated differently by friends and family after the accident. After the accident people with a SCI must now interact and live in a world where they must negotiate time and space differently. Money and equipment now becomes critical for them to normalise and it is often difficult for people with SCI to generate enough income to purchase the necessary equipment and accommodations to create a rich and full life. The participants made the following comments about these barriers to a full life.
Physical Barriers

I think it is getting easier, it has never been too much of a problem. I find that trying to compete in the able-bodied world that is designed, we are talking physical barriers, in terms of physical barriers, stairs all over the place and huge curbs and just really unacceptable stuff, then it becomes a little harder because you are actually physically forced to do things that attack your dignity, like having to deal with stairs. To me it is not bad I don’t mind doing it once in a while but not on a daily basis because it brings out my disability more because when I am in my chair I am competent but to send my chair up stairs because I am strong because I can do it but who likes to show their disability even more, so that’s one reason I try to stay in shape for stuff like that, if you don’t your disability comes on more and more so for some people. —The only time I ever feel disabled is when I come to a barrier that I can’t do easily, like stairs, and I need outside help. Then I feel disabled. (BA)

When speaking of physical barriers GG said, “It is like we are in a world where everything is against us.”

Negative Affectivity Or Created Dependency

In the hospital and many times in the home setting people with SCI are often left out of the decision making process. If this happens the individuals with a SCI can become dependent on the routine and the convenience of having other people do things for them that they could, in fact, do for themselves in many instances.

The whole mindset they try to get you into is not conducive to independence. “D” is a classic example. He’s got people dancing around doing stuff for him all the time and I find that is bad because it gives the rest of us wheelies a bad rap. (BA)

JC thought that the way that the programs where designed in the hospital removed choice and created dependency in the patients:

It is just the whole insensitivity. It is the committal to this flow chart of what this person will need and I think you will have to recognise the fact that it is too complex for your flow chart. This is your big aim that this person is going to make choices, is going to get out on his own, is going to get out of the hospital, going to get out of this program. Years later he is going to be making his own choices so there would be no flow chart. (JC)
Able-bodied people (ABP), including professionals, have preconceived notions of what it is like to be SCI. When an ABP interacts with individuals with SCI, there is a tendency to either pity them or to treat them as a hero, overcoming insurmountable obstacles. Seldom are people with a SCI treated as "normal." People with SCI are struggling with feelings of inadequacy and attempting to redefine themselves as human beings. It is against this backdrop of social stigmatisation that individuals with SCI are attempting to normalise in what is now an abnormal physical and social environment. This process can create a stigmatising effect on individuals with SCI as shown below:

People don’t interact with us as if we were ordinary human beings. We get treated differently. We get treated like a superhuman because look at all we are doing or you are hurt I don’t think you can do that or you poor thing let me help you and you can’t just get a normal interaction with the person. ----I would walk into a restaurant and everybody would shuffle their chairs and two or three guys would stare at me and I found that startling. I had no understanding why and now I have come to a lot more realisation and a lot more acceptance and so now it sort of becomes part of my new self-perception. (JC)

AR commenting on how the stigmatisation process was affected by a person’s pre-morbid personality:

This is difficult because we are bombarded in the world with expectations of what men and women are supposed to be like from commercials and magazines. They portray the ideal person as being good looking, tanned, young, muscled body, toned and successful. It’s an unrealistic image of who you are, yet, for the most part, people want that or desire to be that. A lot of people desire to be equal but they’re not. We need to recognise that we are OK the way we are. Even if we don’t drive a corvette or we happen to be a few pounds overweight it’s not the end of the world. I think coming to terms with who you are as an individual is the greatest area that one needs to overcome. If a person bought into the preconceived, unrealistic expectations of society before their disability, then with
a disability you will be more likely to believe that you're not like this, you don't cut it, you don't measure up. (LN)

JC made the following comments about working as a professional with a SCI:

There are a lot of extremes, you get everything. The most common perception I fight with and it is extremely critical to self-worth is that you can't do something. You have to prove yourself in the work environment because with most guys you are considered lazy until you do something, with quads you are considered incapable until you show otherwise. (JC)

When talking about the stigmatising pressure of society TB stated, “First you need to learn to accept the bullshit that society hands out all the time. The funny looks. The weird questions. The barriers.” RT made the following observations when he was asked if people have preconceived notions about people with SCI:

They might not say they are but their bodies give it away right away. It might not be on their face but their posture or gestures with their hands, they give it away. Anyway you can see the fear, you can smell it, or like you say, they have a preconceived notion about what a handicapped person is. (GG)

I think there’s still a lot of stigma about what disabled means and so there is still a lot of wariness in people. (GG)

If we could remove the physical and economic barriers within some of the private and government programs and such, there is no difference and we need to understand that. I am the same as Joe Blow on the street and I need to be looked at as a person first and not someone with a disability. (GG)

Then LN commented about how he perceives himself:

I guess the way I look at myself is that I have an inconvenience, it is the same as someone else wearing a pair of glasses. That’s an acceptable norm in today’s society. (LN)

**Nocebo Effect**

The Nocebo effect, a term introduced by Weil in 1995, is an acronym for the negative placebo effect the western medical model of medicine has on patients. Weil (1995) claims that doctors and health care professionals can have a negative influence on
patients because patients literally believe the things the doctors and health care professionals say to them and around them.

The way that people with SCI are treated by the ambulance staff, nurses, and doctors can have a serious impact on their psychological state. Even though their logical minds realise that they are still attractive, competent, desirable, and worthwhile, the subconscious mind plays out the fears and misconceptions that they had developed over their lifetime about being disabled with a SCI. Now they feel that they are helpless, unattractive, incompetent, and unworthy. This belief structure is often hidden in the subconscious and operates to sabotage any hope of success in the real world. These hidden fears are now reinforced by their physical body and by the behaviour of the doctors and nurses. Not simply by what is said directly, although there are some examples of direct statements, but also by what is stated indirectly. It is the subtle looks and actions of all those around them that scream, they are diminished. The staff inadvertently reinforces the concepts that individuals with SCI are less than they were before, that they are damaged, and that they will never get better. They are told that the sooner they accept the diminished version of who they are and get on with their life, the better off they’ll be. For example, RT, when talking about his doctor, said, “Anyway, he more or less told me that they didn’t expect me to last a week.” The doctors and nurses are afraid to give a person false hope when in fact they are not certain of the outcome themselves:

One of the faults I have with the medical system and I can’t say I blame them, and if I was in that situation as well, I would probably be doing the same thing. But, what they say is expect the worst and hope for the best but what I am going to tell you is the worst case scenario. (LN)
BA, TB, and JC stated in their transcripts, "Without hope, there is no future." There seems to be a strong push from the very beginning of intensive care by the medical staff to get the person with a SCI to "accept" his condition and not be in denial. The truth of the matter is that nobody really knows what will happen in the first few weeks after a SCI, in terms of return, until the swelling goes down and spinal shock subsides.

**Barrier Of Time**

Time is one of the most difficult things that individuals with a SCI must deal with because it impacts on every facet of their lives. The participants demonstrate in the following quotes how they redefined their perception of appropriate use of time. The quotes from the participants also illustrate the paradoxical relationship that time has with energy, relationships, effort, money, efficiency, and independence.

Time has got to be the thing we have least of now because we recognise that everything takes longer to do. Many things take longer to do, right down to the simplest things. It is very hard to spontaneously recharge as we did prior to the injury. Maybe not such a bad thing the paradox, you suddenly have time to plan or else you waste your day. (JC)

What do I do everyday? I got a 9:00 class. That means I wake up before six, have a shower, get dressed, have breakfast, get myself together and leave and then get in the damn building and to the classroom. And that is every day. And the thing, yeah, it takes me three hours. It takes three hours whereas it takes somebody else forty-five minutes. ----You live within your physical capabilities. If it takes you an hour to get ready, it takes you an hour, so what you were before, what I was before would take me 10 minutes, you don't relate to that because that person is dead and gone. Me is in the chair so you get mad at yourself if it takes you an hour and a half instead of an hour. If it takes an hour that is normal, that is just me. (TB)

That's more than reasonable and I don't have somebody come in at night to put me to bed at certain hours, I don't have to go to bed between 9 and 11 anymore, I can go to bed whenever I want to now. To get me up in the morning is too long a process to dress, shower, all that kind of stuff, I just can't do it, it would take me all day, I would waste my day, so it is not efficient for me, but because of that I have somebody else do that which takes two hours in the morning and it helps somebody else. I need the rest of the day to do my job, to do the other things...
which are reasonable independence. I look at how much I can do realistically without burdening others and how much can I let others do so I can be functional. (LN)

This is one of the reasons why I have so much trouble doing anything. I try to cook my own meals, get up and take care of myself, do a few things, work out a little and that takes almost all day. ---- By the time I have any time to get in there I am so frigging tired that I would rather sleep or relax or watch TV or listen to music. (GG)

I was doing my Ph. D. and I just leaned to the side of academics so as a result I really went downhill in strength and walking around. ---I needed that time doing that so there are only so many hours in the day. (JC)

I swam every day for an hour and by the time you go there, swim, and come back that kills two and a half hours. ------When I was swimming every day I couldn’t get much work done. I would be a little tired and you would almost feel like a nap after. It’s a real paradox. If you aren’t in shape it’s hard to work and if you’re working you can’t be in shape. (CS)

I don’t want to pull them into a relationship when I knowingly know it would be selfish for me to do that because I won’t have time for them. So it is a real paradox that I am in. I am choosing money over women at this point in my life when I desire women. It is like I want the best of both but I can’t have it. (BA)

**Money And Equipment**

The participants in the study thought that money was one of the key barriers for adjustment to SCI. Money allows a person with a SCI the opportunity to buy proper equipment for mobility like wheelchairs, vans, four wheel drives and boats. Money allows them to obtain wheelchairs and accessible housing. It allows them to be able to afford to pay for nurses, attendants, chauffeurs, and maids. Money allows individuals with a SCI to have control of their environment by being able to afford proper equipment. It frees people with SCI to pursue education, relationships, employment and travel.

Money provides the person with a SCI security and freedom.

The next thing is that because of their disability many people with SCI lose their ability to produce and make money and without funding and money you can’t afford clothing, home, a vehicle, pay for gas. I know a guy (SCI) who has a van
but can’t run it because he can’t pay for the insurance or gas so it impacts on your mobility and the way you interact and travel. (JC)

I have three jobs and I find that I don’t have time for a social life because I am so motivated to make money because the motivation stems from the fact that I am afraid to grow old and penniless. It scares me to death. Because there is nothing worse than growing old and being penniless because then all I can afford on welfare is my one case of beer or a couple cases a month and talk about the weather. ---- So it is a real paradox that I am in. I am choosing money over women at this point in my life when I desire women. It is like I want the best of both but I can’t have it. (BA)

Buffering Effect

The “Buffering effect” is a term I have borrowed from Herrick (1994), that he uses to talk about social “buffering,” and I have applied it to the work of Horowitz (1986) and Damasio (1994). Horowitz (1986) theorises that when a SCI occurs, the body is put into such trauma that the ANS automatically compensates and the extreme emotions are stored, suspended, frozen in time. When this phenomenon occurs, the person is unable to experience anger or sexual arousal. This phenomenon or “Buffering effect” is often mistaken for denial because it is inconceivable, by the able-bodied people around them, that individuals with a SCI could be in a pleasant mood after their accident. Several of the participants thought this was a sort of denial that helped them to cope and survive until they were ready to recognise the full reality of their condition.

My self perception did not change the moment I broke my neck and it took many years to mould a new self-perception and I think that is how denial can be helpful until you are ready to accept this new JC you held on to the old JC. (JC)

If you are asking me what my perception is of how I am different part of what complicates that is that it is still changing eleven years after my injury. It is still settling into this emerging. (JC)
Psychological Issues

The stress created by a SCI is tremendous. The body is damaged and the person cannot walk or function properly. The accident creates a milieu of secondary losses including relationships and employment. The participants discussed feelings of anger, feelings of being less than they were before their SCI, and other psychological problems they experienced.

All we had in the hospital was that it taught me how to wheel a damn chair. It didn’t teach me what to expect in life. They might have tried to tell me these things but I wasn’t listening. I didn’t care. That’s the whole thing. How can you inspire somebody to care? What they enjoyed is gone. The desire wasn’t there. I didn’t give a shit. I was just angry at the world. Just mad at anything and everything. I didn’t care. (TB)

BA explaining how he wanted to keep his emotions to himself:

I couldn’t express a whole lot of emotion. She said, “Like don’t you feel anything.” Yeah, I do, but it is not any of your concern. So you have a choice sometimes sharing, you would rather keep it to yourself. (BA)

JC explaining his experience of feeling diminished because of his loss of bodily functions and self-mutilation in the hospital:

I was really hard on myself for a long time and a lot of that anger is destructive too. It sets you back. Anger set in the right direction is OK, but anger against yourself, against your own body, against your own spirit just sets you back. It wasn’t that I was blaming myself for my accident. That is a high level anger. The low level anger to me is just plain mad. If your leg didn’t do what you wanted it to do you would blame your leg and bang on your leg or your head, something stupid like that. I would think to myself, “I must be the only guy that ever did that and it is really stupid, bang yourself on the leg as if that is doing something useful.”—— It is only natural that it is there and the real low level stuff comes out like a rage. ----- You think, how could you possibly shit your pants. You know I am a sophisticated guy, twenty-eight years old, shit my pants. How is that possible? You know Bill Clinton wouldn’t shit his pants and I shouldn’t either. So you get mad. You just get angry. (JC)

When talking about feelings of inadequacy, RT said, “That is when I sometimes feel guilty. I get so tired that I don’t have time to get around to it.” When talking about
survival and avoidance, BA said, “So I got busy and it really had a soothing effect.

Between the music and being busy in the hospital and eating. I didn’t have time to dwell on anything.” When talking about anxiety attacks in intensive care:

I think I was starting to hallucinate as well. Again, I couldn’t tell the dimensions of this room. At times it seemed extremely small and at times it seemed extremely big you know, or the walls were moving in at me. There were times when I couldn’t tell. It seemed as if the whole room was swaying. (GG)

JC had difficulties being alone at night:

I have this picture of myself laying there at 9:00 and we have this nurses’ button, and I am sure I must been constantly pushing on that button, I would ask them for juice, anything, just for human contact. I just didn’t want to lay there and think about it. ----This is the way I was, and here is JC sitting here, what is he doing, breathing. Oh god, he is sickening when he breathes. And turn the TV on, I was watching stuff, no lie, I kept turning it up, the nurses would come and turn it down, I would turn it back up again because I wanted it too loud so I wouldn’t have to think, and I was watching until 3:00 in the morning, they would say what are you watching, I would say, my eyes were this big and round, and also I kept telling them I was in pain so they would keep giving me pain killers and I think to tell you the truth, my gut feeling is, this might sound very odd from a point of view of a neurophysiologist, but I think that a lot of the drugs, anti-spastic medications and pain killers are used also for psychological reasons, they quiet the bad feelings. (JC)

GG perhaps best described how many of the participants felt when they were in rehabilitation in the hospital:

I felt that there I was in the hospital and I was a carp. I was dragged on the bottom. I was a little shrimp crawling along the bottom. I had hit rock bottom. The only other step was death you know. (GG)

**Pre-Morbid Personality**

The importance of the coping skills, attributes, and personal asset and resources of each of the participants was a determining factor in how they experienced the SCI. Their pre-accident personalities acted as a filter to give meaning to their experience of the trauma of SCI.
I don’t know if it’s so much a relation as to the disability that you have. I think that more than disability related issues and everything else, it’s personality and who you are and what you decide and what you choose to make of the situation. And a lot of people say, “Well I don’t have a choice in this and I don’t have a choice in that.” But I know of very few things that you don’t have a choice in. (LN)

Your burning desire keeps you going forward but then you’ve got these hurdles to get over. That is where you rely on your tools, your skills, and your ability to solve problems and get around these painful things. (BA)

I found that by thinking about my life and my philosophy now took away a lot of the pain of what had happened to me-----I think I developed that attitude before from living in ______. I was eager to get up in the morning and do things so that is where that philosophy of you had to do things, you got to get up and do things comes from. (GG)

LN talked about his pre-morbid coping skills.

I had a good parental upbringing and stuff. I decided when I was ten that I needed to start to work and earn some of my own money cause I knew mom and dad couldn’t afford everything I wanted for myself---Basically whatever I wanted to do I had the ability to pick-up and do it fairly quickly so I never had to worry about other people---- I enjoyed my own company. (LN)

LN discussing his pre-morbid self-identity as a factor in his long-term adjustment to SCI:

I had sort of grown up knowing I was OK and believing that I was OK and it didn’t matter what anybody else said or did I believed that I was OK and that I was going to make it. And because of that attitude I’ve been able to continue on and do things. (LN)

Crystallisation

The participants appeared to have certain aspects of their personality magnified and reinforced by the experience of attempting to cope with their SCI.

Those types of personality traits don’t change just because you have an accident. Who you are before your accident is basically who you are after your accident. If you felt the world owed you a living before an injury you are going to think the world owes you after an injury, only more so. (LN)

When asked if experiencing a SCI had a crystallising effect on personality the
participants said:

Yes. You see what is coming out now is always inside of me, but it was the conditions and the accident and stuff and the circumstances of what happened that made me bring this side of me out. The need to survive accelerates it quickly. But the thing is that it was always there but you never used it because you never had to. Now you have to use it to survive, before everything just fell into place. You could use force if nothing else to make it fall into place if you are a very physical person. (TB)

Obviously for him (GG), if that was what he liked beforehand then he’s got it now and this is like crystallisation, beautiful. Maybe he didn’t even know that was what he liked but now he has this time lying in this stryker bed, that’s me, this is beautiful. Whereas, I was just the opposite. I didn’t like this quiet time before. I didn’t like this quiet time before. I didn’t want it and never had to worry about it because I never had to think about how far the universe was because at ten-thirty at night I was so tired I just went to sleep. (JC)

I think an injury can cause a certain trait to become more pronounced if it is something that the individual has control of because what happens with an injury, especially a traumatic injury, is all of a sudden, you feel you have no control. So if there is an area of your life that you think you can still control whether it’s your religion, or it’s your personality, your attitude, whatever, if you feel you can still control, you sometimes have a tendency to draw into it more. So it becomes more pronounced than it was. (LN)

The Crossroads: Decision Time

There comes a time in the rehabilitation process where individuals with SCI are overwhelmed with the cumulative losses and the realisation that this is forever, crashes in on them. This is the moment of world collapse. It may occur within the first few hours or it may not occur until several years after the injury. When world collapse occurs it is theorised that individuals experiencing a SCI resort to their dominant coping skills and personal attributes they had acquired before they were injured. This process of attempting to cope with an extreme situation that they have never experienced before has a tendency to crystallise their personality. At this moment people with SCI make a decision to give up or to try, to live or to die. Suicide is often contemplated but fortunately it is usually
rejected as an option. This moment was indelibly etched into the memories of the participants and further demonstrates the importance of pre-morbid personality and the concept of desire or "the courage to be," spoken of by Tillich (1952). This moment of the decision to carry on after their worlds had collapsed and been destroyed is described by the participants below:

I can consciously remember lying in the hospital a couple of weeks after my injury after I finally got out of intensive care and thinking you know the world owes me and I thought about it for another second and thought, ‘If I died right now the world wouldn't care. If I want to make something of my life I have to choose to do that at this point and time cause the world doesn’t owe me anything. (LN)

Waking up and realising, I like, looked at ceiling, and I am better, and I am going to stay here if I don’t get my ass out of here. Say to hell with it, if am going to stay here---- I am not going to stay in this son of bitching place, I am moving up one step, if nothing else. (TB)

Just because I am disabled doesn’t make me special and doesn’t entitle me to anything extra so I have to make it happen for myself or this world’s going to pass me by and I am going to be some quivering piece of shit in the corner and I refuse to take that avenue and I decided that day one. (BA)

I think that coming to terms with who you are as an individual is probably the greatest area that one needs to overcome and that’s if you had it before you’ll continue on. If you didn’t have it then it’s going to be harder because of all the built in preconceived, unrealistic expectations of the world that everybody else has thrown at you to say that if you’re not this, you don’t cut it, you don’t measure up. (LN)

Long-Term Adjustment To SCI

The second over-arching meta-theme for understanding the trauma of SCI is long term-adjustment to SCI. Long-term adjustment is presented, in this research, as a dynamic cyclical process involving three sub-themes, namely survival, despair, and hope, which will be used to help organise and present the statements of the participants. Long-term adjustment is shown to be a dynamic process occurring over time whereby the
participants cognitively redefine who they are and expand their definition of normalcy to include them as they are now. The participants made the following comments on long term adjustment:

Oh yeah, everybody needs time. The point of accepting the accident is something you go through all your life in a chair because every day something is going to piss you off because you are in a damn chair. That's why. Something that is making you go out of the way, or someplace you can't go because you are in a chair. The acceptance part of it is a lifetime ambition. (TB)

I don't think I will ever completely adjust to my injury. I've adapted to it and I can function within the physical realm that I'm sitting in now. It's not where I want to be because this will never be where I want to be. But, I've adapted to it. I'm working within the constraints of what I have now. ---I've always looked at my injury as an inconvenience instead of a disability. An inconvenience is something I can work around. (LN)

LN does not think of himself as disabled but as having a minor inconvenience.

I think in the whole arena of adaptation it comes down to our own frame of reference and our own terms of what is normal. It's now normal for me to get from A to B by using my wheel chair whereas before it was normal for me to walk or run there. So normalcy----we all have our view of what is normal. We are bombarded by the world by these pictures of these slim men and women who are physically fit and gorgeous and none of us fit into these roles and we sit back and say, “Okay so what's normal for me now? What can I do? What is normal?” That's how I hunt. It may not be my desired preference but that's how I hunt so that's normal for me. I've adapted my rifles and I've adapted equipment to be able to accommodate things that I need to do. It’s not the way I hunted before. I prefer to hunt a different way but since I still enjoy hunting it’s the way I do it. I don't have a lot of other alternatives so you look at things in a different light. You start to recognise that normalcy is what works for you as opposed to what works for everybody else and whether I need a wheelchair to get from point A to point B or whether I can walk is irrelevant. As long as the end result is the same. (LN)

BA, although a high functioning paraplegic, had a self-perception of being disabled. He looked at adjustment as a “journey” and the way he made the journey was in terms of a sports metaphor.

I knew when I hurt myself and I was laying on the track looking up at the clouds I was disabled and that I had to make some adjustments and then once I realised it is like playing a game, once you realise the rules you can organise yourself to do
really well at the game because you have learned the rules. —-I slowly evolved; it didn’t happen until I became disabled. (BA)

GG used the metaphor of an “adventure” to explain his process of adjustment.

At that time my feelings were whatever was done, or whatever one did, it was an adventure and the only way one could lose at this point was not doing anything. It didn’t matter whether you win or lose in an adventure, whether you did something and you would end up getting hurt. The fact that you did something meant that you where progressing. That was my attitude at the time and it probably still is. (GG)

BA is now comfortable with his wheelchair and his self-image.

I don’t think being in a wheel chair is a burden because that is just a vehicle for getting around. —- I look at myself as someone. I gauge myself against what I can accomplish and along those lines and if I am humming along doing a lot of stuff and getting things done. I am very satisfied with that more than the accomplishments that I did when I was walking. (BA)

JC discussing the time course for him to cognitively adjust to his new self-image.

I was confused as to who I was. It took a long time to settle into and as I said earlier, I don’t think it was bad at all for me for 5 years to be in denial of this injury and I think I am glad I was. ------How did that affect my self perception? Or the time course. Let's say the time course of self-perception, I believe in my case, the time course is at the very least has about a 10 or 15 year time course. The thing is coming to an end point, the curve is starting to flatten out but it was very steep initially. And the time constant seems to be the point where it flattens right out. Sometime between now and 5 years from now and I am 11 years post injury, it is just about flat, it is getting flat. I am very happy with who I am now and so on, but it took a long time to come to the new self-perception. (JC)

Adjustment, in the literature on SCI, is shown to be a gradual, dynamic process in which individuals with a SCI cognitively restructure and redefine who they are allowing them to be satisfied in their present circumstance (Crewe & Krause, 1990; Woodrich & Patterson, 1983). The participants’ experiences support these findings and refer to this dynamic process as a journey, an adventure, or a game. The participants identified three basic strategies or pathways that they used on their journey to wholeness. The first strategy is survival; the second is loss of hope or the escape into fantasyland and the
treadmill to despair; and the third strategy is hope. We will now consider the participants' comments about these three pathways.

**Survival**

Survival involves living exclusively in the here and now, one hour at a time, one day at a time, not thinking about the past or the future. Survivors fill up their time with work, sports, relationships, hobbies, music, TV, or any activity that fills the time to the extent that they don't think about and process their emotional affect. Survivors of a SCI struggle to maintain the status-quo and often use coping skills and attributes that work effectively in the short term but do not work over time when challenged by new situations and barriers. Each of the participants in this research appeared to go into survival initially to deal with the trauma of his SCI. In fact, GG and TB claim that they are still simply surviving and believe that this is the best way for them to deal with their SCI. Survival mode allows individuals with SCI time to cognitively redefine their situation, adopt new attributes and coping skills, and gradually assume a new self-identity. Some people who become SCI may be unable to acquire sufficient coping skills and attributes to successfully adjust to an SCI. This may cause them to lose hope and end up on the treadmill to despair. However, if they are successful in adapting and coping, they may embrace hope, accept their new self, and progress towards self-actualisation. Some, however, find it easier to remain in the survival mode.

I had to totally adjust being by myself and still being in a chair. It took me years I would say, because at first I was, all I wanted to do was survive, that was it. As long as I had enough money and all the bills were paid for, that is all that mattered to me. Survival is today. Today is the only one you can guarantee. You don't know what is going to happen tomorrow and yesterday, there is nothing you can do about it. So all you can do is enjoy today. (TB)
Coping is making adjustments and coping is a step in the right direction, the initial step. That means you are staying even-even par. That's called survival. (TB)

TB, when talking about the importance of people and the use of communication skills for survival said, “It is about survival. It is a great advantage to know as many people as possible and to have them like you to make your life easier in the chair.” GG maintained that he was still surviving and using wish-fulfilment as his main coping mechanism.

I am not really worried about the future, in that way, but I know that in my state, I am just trying to survive. But, I guess, the whole thing is trying to dream. And I think I have a future. It is my dreams that allow me to keep going whether I am just surviving some days, which I feel, I get through the day. I guess the dreams bring the reality back to me. What I am really worth. And sometimes I am not progressing half as much as I would like but basically I think I am still going forward. ----That is why I really don’t worry about the future because it will happen if I like it or not. That is why I keep going and feel self-worth. So it may not be in what I do but in what I say. (GG)

LN said, “You have to live in the here and now in order to be realistic about what you can do here and now.”

**Treadmill to Despair**

Individuals with a SCI may not possess adequate self-resources and coping skills to appropriately deal with the trauma of their accident and the multiplier effect of the additional losses as they occur and accumulate. When this happens, they may be cognitively overwhelmed and unable to process all of the emotional affect that has been generated. It must be remembered that at this time the body has just experienced tremendous shock that has impacted on the immune system, hormonal system, and nervous system. The patients, at this time, are also taking powerful psycho-tropic drugs that influence their emotional state. People with SCI may also be confronted with obstacles or barriers that appear insurmountable or their dreams may have been destroyed. When individuals with SCI experience world collapse there is a tendency for
them to resort to their pre-morbid coping skills. If these prove inadequate, they may lose hope and escape by withdrawing and isolating themselves and using obsessive compulsive behaviour like drugs, alcohol, sex, self-mutilation, or overt expressions of emotions (MacLeod, 1988). There is a tendency for people with SCI who lose hope to exhibit habits of poor self-care of the skin, bladder and bowel, diet, and hydration patterns. The neglect of proper self-care leads to health complications and may eventually lead to a premature death because of self-neglect. Suicide rates for people with SCI are five to seven times greater than the normal population (De Vivo et al., 1991). It is estimated that as many as thirty-five percent of the survivors of SCI die a premature death because of self-neglect (De Vivo et al., 1989). TB describes the descent into despair he experienced when he came home and from the hospital and discovered that his wife had left him.

At that time, after she left me, put it this way, I was there for seven months and I left the hospital still on tranquillisers. I was on Librium then. I come home on Librium; I was on Librium for a long time. That was an easy out. It is easy to accept being in a chair, nobody home with you when you are high all the time. You could accept anything if you take enough of them. ---You can’t spend your whole life in your own cocoon type thing and keep your sanity. The only way you can do that is if you are on heavy-duty tranquillisers all the time. ---You live in a fantasy world. You have to because the only thing you know is what is outside your window and what you hear on the phone. Your world is a fantasy world. Everybody’s is to some degree. But not to the extent that you are when you don’t go outside and you are on tranquillisers. (TB)

Similarly, BA describes the process of self-neglect he experienced after he permanently damaged his left arm and couldn’t train or race anymore and the relationship with his friend who was also his landlord deteriorated.

So he is thinking he is something and so I basically get into a situation where I feel shitty and I have to do something. I realise I was f**ked up ten or eleven years ago and what did I do? I got busy. I got busy in something I enjoyed. I started to hand out resumes. I start to find a job. I find a job and I start to get
involved in that so that took me away from a lot of shit I was involved with in the partnership or whatever. I still started to get hassles and this and that and slowly trying to get out of debt. The whole idea coming back to Calgary was to support the financial because I had put every cent of my own money into racing when I lived in BC and stuff. I wasn’t getting any support and finally, I am done racing. I had it. I couldn’t do it any more. I realised what was up and by the fall of 1993. I was not a happy camper. ---I feel bummed out mentally I am still wanting to do racing but physically I can’t. I don’t know how to explain. I don’t feel sorry for myself. I couldn’t believe this is the end and I started to become abusive to myself because before I had money and now I have none. The bills were just amounting to what I owed to my landlord. ---I get out from this deal and on my own and working and trying to make ends meet and I start drinking and get heavily involved with a woman from December till March and finally I just realised that this isn’t what I want. I was waking up hung over and so I wanted to start to feel good about myself, not be abusive to myself because I realised I was being a wimpie. (BA)

When asked why he thought some of the people with SCI committed suicide.

You asked a little while ago when we talked about suicide and the saddest thing in the world I think is the suicide of a person who doesn’t need to do that and who could enjoy the sunshine as we are this afternoon. But something is broken in their spirit, their soul has a bad sprain and unfortunately the soul is what controls you. We can do anything we want. We cannot want what we want. And so your soul gives you what you want and if your soul is wounded there is where you need a rehab counsellor, and it is just a chance thing because you need to hit the guy at the right time. It is a timing thing and that’s dealing with the suicide issue. But, that is the extreme case but not the non-extreme cases of just being sad. (JC)

**Hope: The Healing Path**

Psychological adjustment to SCI may be better understood in the context of hope. Snyder (1989) theorised that hope consisted of two parts, namely agency and pathways. The agency component provides a person with the “will” or “desire” to survive under adverse conditions. The desire then provides individuals with the energy, determination, and perseverance to successfully accomplish their goals. The pathways component provides the means for successfully coping and adjusting ultimately leading to the accomplishment of their personal goals (Snyder, et al., 1991). The interaction of desire and pathways was predictive of psychological impairment of people with physical
disabilities (Elliott et al., 1991). It appears that if individuals lack agency or if they
cognitively do not believe that there is a pathway or means of accomplishing their goals,
they will lose hope and run the risk of psychosocial impairment and depression (Elliott et
al., 1991).

Agency

The theory of hope as outlined by Snyder (1989) was consistent with the
perceptions of the participants who believed that the most important component of
agency for recovery was desire.

That's what you call desire, that process. So you have a dream of who you want to
become, right? What you want to become, who you are is who you are. What you are----If you were totally happy, you would never inspire to go ahead. So the
desire is still there. The desire keeps me going but the pride sets the goals. So
without high goals you, don't accomplish a lot. (TB)

Your burning desire keeps you going forward but then you’ve got these hurdles to
get over and that is where you rely on your tools, your skills, and your ability to
solve problems, to get around these painful things because everything in this
world is either quite painful or pleasurable. ----I have become the master of my
procrastination instead of a slave to it, there is nothing holding me back in this
world, I can do anything. And that is a function of how we are brought up, it is a
function of how we look at ourselves and how we feel about ourselves and how
we allow people to treat us, that is the biggest thing. (BA)

I've always believed that I will do what I need in order to function and live
independently and as full a life as I can regardless of what other people think.
(LN)

You need imagination, will and desire and you can accomplish more than you or
ABP's around you would suspect. ----Don’t buy into the psychosocial stigma of
inferiority and inability to do some things. It’s simply a different way of being.
Many accept the myth that it is over, therefore for them it is. (GG)

The participants viewed desire as the most important personal attribute of the
agency component of hope. They also identified the following personality attributes that
they believed contributed to their agency and ultimately to their long-term adjustment to
SCI. These attributes tended to work together in concert to create a positive motivational state. The participants in this research stressed the importance of taking personal responsibility for their self-care. This involved all aspects of their lives including exercise, nutrition, skin care, transportation, education, work, and recreation.

The biggest thing for me is, are you healthy? If you are healthy then you can volunteer, work, go to school, participate in recreational activities, and you are happy. That is important. When I got out of the hospital I swore to myself that I was going to drink properly and eat properly and I was going to keep my bladder basically infection free. I personally think as a general rule that doctors prescribe too many drugs and we need to learn different methods of coping that are healthy to us. I don't take drugs right now. I haven't taken drugs for probably 15 to 18 years and for the most part I am healthy. The body will adjust to a routine. You work around what your body is telling you but for the most part I think the closer that anybody can get to being completely natural the better. (LN)

Basically you have to take responsibility, you eliminate as many secondary injuries or things as possible, bed sores, situations where there is a health hazard, so that always figures into your equation. (CS)

I don't let a day go by without exercising. The only time I don't do my exercises is when I am really sick. Flexibility is so important. If it means taking a half-hour in the evening to loosen up, stretch or even go to an exercise group whatever it takes this is something that really needs to be done. (GG)

As an adult we have to be accountable. They give you drugs. We have to be accountable. You are in a different state. You still have to be accountable to yourself with personal health. So, by looking after ourselves and treating ourselves as a temple and keeping our temple clean and healthy in every facet, physical and mental, then we realise the only thing holding us back in this life is me. (BA)

I think you need to take personal responsibility, not so much for the accident, but for your response to the accident. (LN)

The participants of this research have suggested that taking personal responsibility needs to be pursued realistically, in terms of a life-long perspective, focusing on moderation and balance instead of a short-term, no-pain no-gain type of mentality.

Even though I was exercising in a positive way at first I think I overdid some things, thinking that would really speed things up. This is a long time later but, I
have some sore joints, lower back, a hip, which really bothers me bad, knees and then for complete quads their elbows really get bad because they flip them backwards. I think, recognise that, recognise that your joints are not unlimited mechanical machines. That, in fact, they have some very real limitations on the joints and cartilages and so on so hold back a little rather than getting really focused on wheeling. I might think it might be really cool to wheel 40 clicks today even though my shoulders are sore from yesterday. If your shoulders are sore from yesterday, they are trying to tell you something. “Don’t do it.” “Temper your enthusiasm. (JC)

There is always a trade-off as to can I do it and is it productive for me to do it. So, you weigh out the productivity as to the time constraints and come to a balance as to what you feel is reasonable for what you are doing with your life. (LN)

The participants stressed the importance of maintaining an internal locus of control:

Through this all, even though you believe in God you also believe that AR was going to be okay, that I was going to take care of business and that I wasn’t going to let this defeat me. (LN)

They also discussed the importance of developing good communication skills:

I need to become more responsive to other people. I need to understand other people better. So for me it is a continuing to grow. ----My accident taught me, forced me actually in showing me I needed other people. I needed people to do things for me that I would normally do on my own. So the accident has taught me a lot in the aspect of how to deal with people, how to talk with people, how to appreciate people, to actually sit down and listen and to hear what people have to say and to care about what people have to say was something I never did before. (LN)

Now I am much more sensitive. I watch my words maybe too much. So now I am constantly saying I should have said that. I try and read between the lines constantly where I am picking up on this person’s attitude, not just what they said but where they are coming from in the world at this moment. (JC)

Your ego should not be damaged and your pride should be intact when you ask someone to help you. (GG)

The participants discussed the importance of using creativity to solve problems.

Necessity is the mother of invention because I can’t always rely on other people. If a problem comes I can figure a way to make it work somehow. (BA)

That is the thing I tried to get through to them that it is not over. All you need is a bit of imagination and just the will and desire to do these things and you know
you will be surprised what you can actually achieve. I am telling them the
disability has almost nothing to do with it. There is always ways around things.
(GG)

The participants discussed the paradoxical nature of risk:

No you don’t want to try that if it is too dangerous. I am saying allow the person
or encourage them. They’ll find out soon enough they aren’t going to be able to
do the iron man marathon or paint a Picasso picture or something like that. They
will find out sooner or later they just don’t have the talent. (JC)

I know that when I moved out on my own and started to do my own things my
parents were petrified that things were going to happen to me and that I was going
to be at risk. So the worst thing someone can do is not risk. (LN)

The participants of this research each displayed a deep and abiding love for themselves
that appeared to be a result of their belief structures and perceptions of themselves, which
they had internalised before their accidents:

I know that God loves me the way I am. Therefore I can love me the way I am.
(LM)

I put all my faith into myself, why would I put all my faith into somebody else
who wouldn’t even exist, are they going to put bread on my table, are they going
to make me feel pleasurable. Maybe by singing all day long that God loves you
and knowing that somebody loves me, but to me I look beyond that, I love myself.
(BA)

Just start saying it out loud. I am a good guy I am capable of doing a lot of things
and I am doing a lot of things and I am going to succeed. Now just say these lines
over and over again and don’t think about the situation. Don’t think about you just
pissed your pants and are soaking wet. Just keep saying, “I am a good guy. I am
capable of doing good things.” And you are going to. And you know what?
Pretty soon it becomes part of your deep inner thoughts. (JC)

I had two options to begin with. The first one was riding myself for the rest of my
life, or forgiving myself because I made a mistake and I can’t change that so right
away my first option was to forgive myself. I can’t change circumstances by
being mad at me for the rest of my life because I made a mistake. (LN)
Pathways To Long-term Adjustment

The second component to hope is pathways. Pathways provide the means for successfully coping, adjusting, and generating a wide range of options for the person with a SCI to successfully attain personal goals. The participants commented on the following coping-skills that they found useful in improving their lives.

Emotional regulation. They discussed how controlling one’s temper and using the emotions generated by their anger in positive ways benefited them in many situations:

Anger against yourself, against your own body, against your own spirit just sets you back. My advice would say, if you can see it at your stage, take it easy on yourself because you will do the things you want to do more quickly and you will get to the goal you are aiming at more quickly if you don’t take your anger out on yourself mentally or physically. Try to redirect that anger, re-channel it, it is only natural that it is there and the real low level stuff comes out like a rage. Try to redirect it. Don’t be hard on yourself. (JC)

No sense wasting your breath if it is not going to help you. The worst thing is getting pissed off, you are just going to run yourself down, not who you are getting pissed off at. It doesn’t bother them a damn bit, they can walk away and if you don’t get rid of it, it stays with you, so you have to sluff it off. Get rid of it. (TB)

They would never do it the way I would do it myself. That’s part of learning how to communicate with people and saying, “Okay how much of this is my own idiosyncrasies and what is reasonable to someone else.” (LN)

Willingness to change. The participants discussed the importance of being willing to give up previous goals and learn to change and adapt:

My life has changed a great deal because of my injury. In many ways I feel it is to the positive. You learn to compromise your standards to a certain extent. It was frustrating to begin with. Again it’s part of recognising and learning who I am and myself recognising that maybe being a total perfectionist isn’t all it’s cracked up to be and that’s part of the maturing process. (LN)

Cognitive restructuring. The participants talked about a gradual process of
re-defining who they were and what their definition of success was:

For those first critical five or six years after an injury you really don't start to find out who you are for at least five years----This is a new way of thinking for me. So this is a post spinal cord injury way of thinking for me. To hear someone say something and just think, I would like to say something like that---Try to say things that are purposeful and be nice and so on. And just be more aware of human interactions-----Before I was more self contained and I would do what I did. (JC)

What's normal is what works for me. I don't have a lot of alternatives. So you look at things in a different light. (LN)

That is why I really don't worry about the future because it will happen if I like it or not. That is why I keep going and feel self-worth. So it may not be in what I do but what I say. (GG)

Planning. The participants talked about how critical planning was since their SCI:

I make my moves very carefully, not just physical moves but where I am going and what I am going to say and to who. (JC)

So that spontaneity is still there but it takes more planning to get a project underway, and you don't waste time. (BA)

Goal setting. The participants stressed the importance of setting goals:

I don't know about attaining the goals. I set far more goals than I attain but I make no apologies for that because I think it is in the hunt that life is experienced and fullness is experienced and very often the kill is very anticlimactic. And I think what I do all of the time is set goals, some more realistic than others, but I am constantly setting goals and doing something about them. I tried all kinds of things, hobbies, various hobbies and stuff that I will make a go at and I still never fill any of them out. I figure at any one time I have a dozen things on the backburner. ---- I think setting goals and working towards the goals are important and don't worry about attaining the goal. It doesn't have to be realistic in anyway whatsoever. I think the realism will fall out of the doing. (JC)

You set yourself a goal out there somewhere and then you take the little goals and strive towards it. Day to day even, can I get to class tomorrow on time, that kind of thing, little things and find enjoyment in the little things. Because you have to have some enjoyment in life or you are going to burn yourself out. Depress yourself if you don't find some enjoyment out of the little things you do. I found that when I let go of my goals it was so easy to stay in bed all day. All the time,
you have to, to accept things. That's the whole thing, the whole idea is setting some goals that are obtainable and reaching them and setting more and keep going and going and going, getting yourself up and out of that stupid hole. (TB)

**Direct action.** The importance of taking direct action to obtain goals was described as follows:

This is the whole key to recovery. I think you have to get busy in a recreational leisure way, doesn't matter what it is and it starts to develop physical attributes. So you get some strength and then what happens, with that strength, you start to build confidence. With confidence you can start to go out to the outside world. (BA)

I have seen in peoples' lives how becoming employed or being involved in something, well say a recreational activity, has turned their life around because they actually see that they can do something. (JC)

The only way to lose is to do nothing. In an adventure the journey is the thing, winning and losing is immaterial. (GG)

**Hope vs. Denial**

Five of the participants were told that they were total lesions and that they would have to live in an institutional setting. All six participants were told that they would never walk and that they had to accept their wheelchair. Today all six participants live independently and two of the participants can walk with forearm crutches. Hope is often confused with denial. However, there can be a risk involved if individuals with SCI set a goal of walking then they do not get any return.

I have seen people who committed suicide because the only thing they are living for is walking and if that doesn't happen then life isn't worth living. They need to understand that life can be worth living no matter where you are at. (LN)

When GG was asked how he maintained his hope in the hospital he commented:

At that time I was convinced I was going to make it back and that is what I had to look forward to was that I was going to get back to standing on my feet. Not really realising that was going to be impossible from then on. (GG)
When asked if this was denial, RT stated, “It was not denial. It was that I was just ignorant of the fact that I had done so much damage that I would be in that position.” If a person believes that he has hope, however slight, that he will be able to walk again or become strong enough to live independently, it can act as a tremendous motivator to work hard in a rehabilitation program. JC commented:

Denial is a great motivator. If you stamp that out --- that motivation --- it might not be serving the function you want to. You think that once you get rid of this denial that this guy is suddenly going to get keen and get going on with his life and doing what he can. It just might have the opposite effect. It’s that denial that is getting them moving. (JC)

**Relationships**

Herrick et al. (1994) found that there was a paradoxical relationship between relationships and dependency. Relationships have been shown to inadvertently reinforce dependency and increase stress and psychosocial impairment for people with SCI (Elliott et al., 1992; Rook, 1984; Turk et al., 1992). However, if relationships are based on worth then they can have a positive effect on individuals with SCI (Krause et al., 1997). JC was the only participant who maintained what he called a “strong” and “very satisfying” relationship. When asked why he thought his relationship worked he explained that it was a combination of several factors. JC credits much of the success of his relationship to the quality of the relationship that he had with his wife before his accident. After the accident he was determined to keep the marriage alive and he and his wife continued to share responsibilities and activities, while maintaining their independence and outside relationships. JC also thought that his sense of denial and a belief that he was going to get more return and completely recover helped him to continue trying and helped him not to allow his life to revolve around his injury.
Denial. I didn’t believe for the first five years at all that I was going to remain this way----I did it instinctively because of the denial I was in. You don’t want the whole world to be centred around your injury because her world would crumble and knowing this I avoided that. For those first, critical first 5 or 6 years after an injury you really don’t start to find out who you are, you don’t know this new person. (JC)

So for that critical time period we split the work quite a bit. She would cook and make the meal, and then go do something. I would clean up the kitchen. That is something I could do. I would even help with laundry, and we split the work, in fact I would say 50/50. (JC)

My wife and I have very important interpersonal relationships with people other than each other and it sets up kind of a framework for both of us. Our social activities went beyond each other. We are like two people in this big framework instead of the big framework being each other and it is almost like our marriage has been held together with relationships with others so I am very close to her family. (JC)

I would say let’s go skiing and she would say what are you going to do? I’ll take my books. So we would drive out to Fortress or Lake Louise and I would sometimes just sit in the car and read my physiology textbooks and drink coffee and she would ski for 3 or 4 hours and so she came in with the sense that I had participated with her----She would say she wanted to go running and I would come with her and I would read my book or something and she would run for a couple of hours. She ran her first marathon in 1988. I was spinal cord injured in 1985 and mostly because of my pushing, I insisted she went running everyday and get out of the house and she was doing all the things that she had been doing, her life didn’t change. But, she had this feeling that we were doing something together and we were doing her thing, not my thing. We went out and did it and now looking back on it, that was the smartest thing I could have done, I didn’t even know it was at the time. It just worked out that way. (JC)

Another part of the independence was I was going to University and doing the graduate study thing, getting my Ph. D. and that is a big job and very time consuming. What it does, was I had my independence, she would be off doing her thing, so you didn’t even want her to look after you. (JC)

My wife and I weren’t going to allow a SCI to destroy our marriage. (JC)

The other five participants wanted to be involved in a meaningful relationship.

However, they were unwilling to compromise their standards and maintain relationships that were not emotionally fulfilling. At the time of the interviews and to the present all of the
participants except for JC live alone by choice. The participants were asked why they thought they were still alone even though they wanted a relationship.

Relationships are much more complicated when you are disabled. It is because when one piece of the puzzle drops away to the wayside it puts the whole thing out of balance and in jeopardy. Relationships, because everybody who has a disability is a little different and that has a profound effect on relationships. ---I would rather live alone and be moderately happy than live with someone and feel inadequate. (BA)

A lot of people break up because of the mind set, “Well I didn’t marry someone who is disabled. I married someone else.” That’s some of it. Some of it is that the relationship wasn’t in great shape prior to the accident and this was just one more thing that broke it up. ----Relationships are somewhat harder in a chair, I think, and I think there’s still a lot of stigma about what disabled means and so there’s still a lot of wariness in people. ----I am afraid to a certain extent that I am going to get hurt again, but I also know that if I don’t try it, I will never know the joys of a relationship either again. We are in this dichotomy of pain and pleasure. (LN)

If you are like me, I long for solitude. Yet, I also long for this perfect relationship and there is no way you can have both. You’ve got to compromise on both things almost. (CS)

People who are living a long time in a chair, who have got their shit together, and got their head working properly and they don’t know if they want to put anybody else through the trouble of being with them. Or no matter, once you marry a woman, you are automatically being compared against every other guy, not just guys in chairs anymore co-integration into the normal society. You are compared to all husbands, not just the guy in the chair. ------More than likely she will drag you down, if you want to keep going ahead, it has to be somebody who is going to inspire you not drag you down. (TB)

When the participants where asked what they were looking for in a relationship they responded in the following manner:

I want everything. Somebody I can talk to and who would understand me and will say something back to me which will make me think. And somebody, a good-looking women which, I would be proud of to be near. It doesn’t have to be number one in the world type of thing, but somebody who physically, intellectually and spiritually makes you proud to be with them and makes you happy to interact with them and when you wake up in the morning you are damn proud to be with. (TB)
I hope I haven't become biased but if I am going to have a relationship I hope it is going to be with an older woman, not a girl. As good looking as they are, I know that I am going to have problems with them due to their inexperience. If I am going to have a relationship with a woman, I want it to be with someone who's experienced and knows what she wants and that knows what a man wants and will give it to him, and appreciates that I am able to help her achieve her goals. (GG)

The participants spoke about how relationships with women often made them feel inadequate and less than they were before their accident:

I am thinking, especially when you talk to young women, I look at the woman and I think, I am infertile now and this woman hasn't had kids yet and this might just break it up three years down the road so why even start. (TB)

When I asked my wife if part of the reason she was leaving me was that I was disabled she said, ‘Well you are not as big and as hard as you used to be and your hands are so stiff.’ It made me feel like no one would ever want to make love to me again. (CS)

For me, my biggest thing is I haven't orgasmed or had a physical release since I was a teen. (BA)

**Sexuality**

The participants discussed their sexuality very candidly. Their sexual pleasure seemed to be generated by psychological and visual stimulation rather than through physical gratification. Much of the pleasure the participants received is from their partner having pleasure and verbalising this pleasure. As GG said, “I like to watch.”

Even though you can't walk, or do a lot of things AB’s do, I think I have overcome that. I think I have gotten past that. There is a big machismo about being a man and I have gotten over that and try to do what my spirit tells me and try to do what I can as a human being. I consider myself as only being half a human being, a woman is the other half. She possesses the qualities that make me complete and when I bond with her, or make love with her that's when I feel more like a complete human and part of it is getting over some of things society perceives us as being. And, when you really get down to it you realise we are all human beings and she is just a complete opposite of me. It makes me complete as a human being. (GG)

Something I want to talk about is that the visual stimulation of a beautiful woman is very important for a relationship because I cannot feel my penis very well and
often I can’t ejaculate. So, for me to get my excitement, it comes from giving them satisfaction and that gives me the satisfaction. And part of that is visual and then the sound, smell and touch I could feel with my hands. The visualisation though, is really important for increasing the sexual feelings in the relationship. (CS)

Compared to before, I believe, I have more regard for my partner, more interest in what my partner wants, in what she needs, not self-centred at all because not having any feeling is totally her gain. --- The more pleasure you give her is not just to her, it is the more pleasure you get. It is not a matter of you giving. That is your pleasure. And if you don't give, and if she doesn't have none, she is not enjoying herself, you're not enjoying yourself. It is a matter of you giving to yourself. (TB)

I spend a lot of time on foreplay, then I inject my dick and spend some more time on foreplay. It is really nice having that kind of patience sexually because now I have so much more ability to focus my attention on the woman. And the really nice thing about it, that no one ever tells you, is that when you start applying your attention to a woman and giving her pleasure. Her pleasure is very verbalised. My pleasure comes from giving her pleasure. As she becomes more aroused all my senses come alive and I can see, smell, taste and feel her excitement. It is all psychological pleasure for me because I can’t ejaculate. (BA)

Unfinished Business

The “buffering effect,” as applied to the findings of Horowitz (1986) and Damasio (1994); “denial,” as referred to by Caplan (1987); and avoidance as referred to by Horowitz (1986), are other names for a process that is referred to in this research as “frozen in time.” When people with SCI are overwhelmed by more stress than they are able to cope with, the body, it is theorised, automatically stores the affect. This process appears to be instigated automatically by physiological and psychological means to protect the person from being emotionally devastated by the losses. This emotional time-out provides the person with a SCI sufficient time to cognitively re-define exactly who they are and marshal sufficient coping skills and personal resources to adapt to their new situation. The stored affect, “Frozen in time,” remains dormant until triggered by an event that releases these emotions and brings them to consciousness. This event can be a
physical barrier, lack of money, an illness, or a death of a loved one. Emotions, like anger, and issues, like feeling incomplete, that the person with a SCI thought had been dealt with many years earlier, can suddenly reappear. The concept of having to “Defrost Unfinished Business” or deal with issues that had been stored until triggered by an event was the final missing piece of the puzzle that I needed to understand before I could conceptualise the process of long-term adjustment to SCI.

I had slowly improved and progressed physically, emotionally, and financially from my accident until the end of 1993. I had completed my candidacy exams, my proposal had been accepted, and I had received approval from the ethics committee. I was completely out of debt, had RRSPs, and I had a beautiful girlfriend. I thought that life would continue to improve in a linear fashion. However, this was not to be the case. In a two-week period in January of 1994 my father died, my supervisor moved to Australia, my girlfriend broke up with me, my typist of four years moved to Vancouver, and I moved into a new Condo. In the next year I lost money in the stock market and my truck got stolen and was never recovered. The losses of all of these things that I loved or cherished accompanied by the stress of doing my Ph.D. began to overwhelm me.

In the fall of 1995 I was stopped at a red light and a drunk driver hit me from behind doing over thirty miles an hour. My neck was damaged again and it took several months of therapy to recover. In 1996 and 1997 I had three hernia operations and in 1998 I had a perforated ulcer that required emergency surgery. I became discouraged and depressed as my physical abilities seemed to be deteriorating and the self-imposed pressure for finishing my Ph.D. increased. I didn’t understand what was happening to me.
At this time I read several articles about the buffering effect, hope, agency, pathways and counselling people who had experienced severe trauma. Reading the articles put my experiences and the experiences of my fellow participants into perspective and allowed me to glean a new understanding of what was happening to me psychologically. The readings and the events of the previous five years reinforced the concept that a SCI is never over and that as TB said, “Adjustment (to SCI) is a lifetime ambition.”

It wasn’t until a fateful April afternoon in 1998, when I was able to diagram the model for “Understanding the Trauma of SCI,” that I realised I had been withdrawing from my responsibilities and isolating myself from my family and friends. I had been attempting to escape. I now understood that the anger I had been experiencing, the low-level anger talked about by JC, was really unfinished business, emotions that I had not dealt with since my accident and rehabilitation. Now I understood that long-term adjustment to SCI was a dynamic, on-going, cyclical journey and not a final destination.

The themes presented and discussed in this chapter have been arranged and conceptualised into a model that explains the phenomenon of “Understanding the Trauma of SCI.” This model will be presented and discussed in the following chapter.
CHAPTER FIVE

DISCUSSION

Cook (1979) suggested that dealing with a SCI is a lifelong process where there is no endpoint where all is well and conflicts between desires and abilities are resolved. Corbett, (1980) further added that dealing with a SCI is a lifelong battle, a monumental inconvenience. While Hablin (1968) pointed out that psychological adjustment rather than a person's intellectual capacity, level of break or completeness of break was the critical factor in determining if a person rehabilitated successfully. He also maintained and that, without an acceptance of the SCI, the best physical therapy or vocational training was of little benefit.

This study explores what happens to individuals when they experience the trauma of SCI. In order to know what interventions or counselling strategies are appropriate for long-term adjustment to SCI, I believe that it is necessary to understand SCI from the perspective of people who have experienced SCI. Trieschmann (1988) concluded that the interaction of psychological, organic-biological, and environment factors of SCI or \( f(P,O,E) \), could best explain the behaviour \( (B) \) of a person with a spinal cord injury. Or simply written, the formula is \( B = f(P,O,E) \). To properly explain the SCI phenomenon, I needed to be able to probe deeply in order to explain \( B \). To facilitate this process I used a qualitative research design as this methodology enhanced the production of sufficient data to formulate a grounded theory for "Understanding the Trauma of SCI."

The discussion, presented in five parts, will start with "Understanding the Trauma of Spinal Cord Injury," which includes the presentation of models developed in this research. Then the implications for counselling, including the importance and process of
"Defrosting Unfinished Business" and the implications for counselling males will be presented. Next, the limitations of the present research will be discussed followed by previous problems involved in SCI research design. In conclusion, implications and recommendations for future research on SCI are discussed.

Understanding the Trauma of Spinal Cord Injury

"Understanding the Trauma of SCI," the grounded theory produced by this research, is a synthesis of information developed from the themes generated by the participants and my interpretation of the literature on SCI. This topic will be addressed in two parts: namely "World Collapse" and "Long-term Adjustment to SCI." To enhance the understanding of the grounded theory generated by this research, models have been formulated that are to be used in conjunction with the text. This section of the Discussion will roughly follow the same format as Chapter Four and closely mirror the different models. However, there will be some differences and inconsistencies because some of the themes have been combined to prevent duplication, enhancing the explanation of the grounded theory. It must be remembered that many of the themes and operations comprising the model for "Understanding the Trauma of SCI" occur simultaneously and in parallel, making explanations of the model difficult because this information can only be presented and discussed linearly.

**World Collapse**

The phenomenon of "World Collapse" is presented as a model in Figure 1. Individuals with SCI experience their accidents and subsequent rehabilitation differently because their pre-morbid personalities act as a filter, giving different interpretation and meaning to their lived experience of SCI. Figure 1 was designed to be used in
conjunction with the text to facilitate understanding of the discussion of “World Collapse”

The Lived Experience

The “Lived experience” is a description of significant events that the participants in this study identified as being significant in terms of their adjustment to the trauma of SCI. Since the initiating event was the accident itself, the organic-biological, environment, and psychosocial elements all flow from this single emotionally charged occurrence.

The trauma of the accident. The accident remains vivid in the mind of each person who has experienced a SCI. He can remember the exact time and every detail of his accident unless this tragedy was further compounded by a traumatic head injury. Immediately, he is confronted with two of man’s worst fears, impotence and paralysis. A SCI triggers a cascade of secondary losses, places him in a hostile environment, stigmatises him, and creates a situation where he questions his self-identity. Immediately he panics and asks himself questions. “Am I going to die?” “What’s going to happen to me?” “Will my wife/girlfriend leave me?” To compound everything that’s happening he is given large doses of psychotropic drugs like Morphine. He can’t eat or drink anything and he is not allowed to sleep. These events are indelibly etched into his memory, frozen in time.

Organic, biological issues. Within seconds of impact the person with SCI experiences a total loss of sensation and use of his body below the point of the break on his spine. Sensations of touch and hot and cold are gone. Control of bowel, bladder, and sexual function is lost. In quadriplegia, the body even loses its ability to produce tears.
Far worse, if the break is high enough, the body loses its ability to breathe. The immune system basically shuts down and becomes ineffective making him vulnerable to bacterial infection. Muscles, controlling the lungs, no longer function properly and the diaphragm now performs this function. This creates a serious problem because it allows water to collect in the lungs, which can cause the person to drown or get pneumonia. The person with a SCI must be catheterised and this facilitates bladder infections because the bladder cannot empty completely.

A hospital is one of the worst places on earth to be if you are trying to avoid bacterial or viral infection. People with SCI are particularly vulnerable to becoming infected because the function of the immune system has been severely reduced. The body is an amazing organism and has automatic back up systems and is designed to survive. When a person experiences extreme trauma the body, it is theorised, compensates and causes a change in the autonomic nervous system (ANS) that inhibits emotions like anger and sexual arousal (Hohmann, 1966). Horowitz (1986) and Damasio (1994) describe this process as a “Buffering effect” and theorise that the body realises instinctively that it is unable to process the emotional affect generated by the stress at that particular time. It therefore inhibits the person’s ability to experience that emotion at that particular time. The affect is then automatically stored, frozen in time, to be dealt with later when the person is cognitively better able to deal with it (Damasio, 1994; Horowitz, 1986). This allows the person to focus on survival, important because the initial effect of SCI is that the person is basically helpless. At this time without good intensive care the person with a SCI would soon die. In fact, this experience often brings the person with the SCI face to face with the question: “Do I really want to live if it means living like this?” The loss of
physicality promotes feelings of incompleteness and disconnection from the body. As CS observed, “I felt that I was just a head on a pillow,” while GG stated:

My whole world was from my neck to the top of my head, as that was the area I could see and hear and feel. The rest of my body was in total darkness. Not the darkness of not being able to see but the darkness of not being able to touch or feel or respond anymore. It felt cold. It felt dead. It felt as if there was nothing there any more. (GG)

Environmental issues. The goal of rehabilitation is to help individuals with a SCI recover from their accident. The rehabilitation experienced by my fellow participants and myself is the typical “Western medical model” where the emphasis is on the physical recovery. BA commented on this when he said:

The professionals have no idea of what is going on. They know the physiological aspects and OK the bones healed, the tissues healed, and the scars healed and blah, blah, blah, but they don’t deal with the psychological aspects and nobody really did. So they just throw you in with a bunch of other gimps and hopefully you will sort it out for yourselves. (BA)

Rehabilitation, seen in this context, has a singular focus, to create an environment that enables a person with a SCI to acquire as much physical return as possible and then teach him how to become as independent as he can. Unfortunately, rehabilitation programs are designed for the convenience of the hospital staff and not the patients.

Instead of fostering independence the patient is placed in a situation where they become dependent on the system. The patient is told when to get up, when to eat, when to go to physiotherapy, occupational therapy, and recreational therapy, when to go to bed, when to have bowel routines. (JC)

You feel like you have a real loss of control of the environment. You have to get up at a certain time to eat and you gotta work out at certain times---they come in the middle of the night and stick a tube in you. ----next thing you know you are being poked and prodded by whoever, whenever and after a while, holy shit, so I just accepted it. That’s the deal. (BA)

The hospital imposes when patients have their medications, when they are turned, and when they are catheterised. Without warning individuals with a SCI are sent for X-rays,
MRI's and other procedures. They are subjected to examination by large groups of doctors, student doctors, RTs, OTs, and PTs. Often in these examinations the covers are pulled back revealing a patient's nakedness further emphasising his helplessness and vulnerability. The doctors and nurses often refer to patients as, for example, the quad in 4-D. People with SCI are often worked on and treated as objects and are generally not participants in the conversation. In fact, the patient loses control of the environment and he is seldom involved in critical decisions about his rehabilitation or medication. This process desensitises the person and eventually he becomes programmed and routinised. This leads to a decrease in the energy level and responsiveness of people with SCI in the rehabilitation setting (Trieschmann, 1988).

Slowly the person with a SCI learns to adapt to the environment in the hospital. The difficulties involved in the daily tasks of living like getting dressed, transferring out of bed, opening a door, or grooming are overwhelming at first. In fact, these basic skills are beyond the abilities of many high lesion quadriplegics. The person with a SCI is encouraged and trained to perform these tasks in the hospital. However, this is an artificial environment and does not prepare the patients for the real world. When the patients go home for a weekend, go on an excursion to a hockey game, or go shopping, they are brought face to face with the reality of a world that has barriers they cannot overcome themselves.

The rehabilitation goals for the practitioners and the patients in the rehabilitation setting are often different (Taylor, 1967). Taylor (1967) demonstrated in his study that the main goals of the patients were to get stronger while the practitioners' main goals were to teach them how to use aids. When patients try to initiate their own ideas and
timetables they are met with resistance. Patients are often punished if they complain or try to take control of their own environment.

The patients are seldom consulted about what they want, for example, sex education classes, where one class fits all from 19-year-old singles to 50-year-old marrieds. These classes were universal and the assumption was made that a cookie cutter approach would satisfy each person’s needs.

I didn’t agree with the sexuality classes; they turned me off and isolated me because I didn’t want, or need, that information then. I think that counselling is more complex than rounding up eight quads and having a class on sexuality because of the diversity of ages, injuries, abilities and current marital status. I would have preferred to have been counselled one on one because everyone has different needs. (JC)

The environment is critical in rehabilitation. Trieschmann (1988) stated that a person’s behaviour or adaptation is a factor of the interaction of the psychosocial, organic, and the environment. Raferty (1991) suggests that it is the person in interaction with his environment that is the critical feature of all rehabilitation efforts. Individuals with SCI usually have little input into the institutionalised environment and rehabilitation process, creating a situation in which the patient becomes routinised, desensitised, and dehumanised. The environment in rehabilitation achieves the opposite goal from what was originally intended, that is, dependence and stigmatisation rather than independence and a positive self-image.

Psychosocial Issues

The participants of this research identified five general areas where they experienced psychological stress, created by the psychosocial environment in intensive care and rehabilitation, which include secondary losses, negative affectivity, the look or psychosocial stigmatisation, the Nocebo effect, and the misdiagnosis of depression.
Secondary losses. The primary loss for people who experience SCI is the loss of their body and bodily functions. The literature on adjustment to SCI indicates that there is no correlation between organic variables such as level of break and degree of impairment and long-term psychological adjustment (Kennedy et al., 1995). It appears that adjustment to SCI is dependent on how people with the SCI uses their personality to filter the experience of SCI to come to an understanding of what that experience means to them (Frankl, 1984; Oliver, 1981, 1988; Trieschmann, 1992).

The physical loss that occurs because of the accident acts as a catalyst to a tremendous series of losses. These losses include employment, relationships, friendships, role definition, status, prestige and future possibilities. The number and degree of these losses hinges on the pre-morbid coping skills, attributes, and personal resources of the person experiencing the SCI. The psychological impact of those losses hinges on the meaning the person experiencing these losses attaches to them (Elliott et al., 1991; Frankl, 1984; Oliver, 1981, 1988; Trieschmann, 1988).

There appears to be a multiplier effect when it comes to evaluating the degree of psychological impairment. For example, in severe trauma the impact of three significant losses does not appear to be three times worse than one loss. Depending on the meaning attached to those losses, the impact may be more like 3 x 3 or nine times the psychological pain and impairment. This is because each new and additional loss impairs the person’s ability to cope with the stress of a previous loss. If the losses happen in rapid succession and if there is no conceivable solution or end point for the problem, the person’s capacity to cope is quickly overwhelmed and he will experience world collapse.
Negative affectivity. Negative affectivity is a dependency created by people around the person with a SCI when they do too much for him. This process is more likely to occur in situations where the relationship is especially strong as in a mother-son or husband–wife relationships (Watson & Clark, 1984). The environment itself can also contribute to creating situations in which people with SCI abdicate responsibility for their rehabilitation. The environment and the people around a person in a rehabilitation situation often unwittingly conspire to foster dependency, despite the best of intentions (Watson & Clark, 1984). An example of this often arises when a person is severely injured and is advised to sign over his power of attorney. A lawyer, witnesses, and a justice of the peace can come to the hospital and power of attorney can be given to his spouse or parents. The hidden message to a person in this situation is that he is going to die and that if he does not die, he will never be able to take care of himself again.

When people visit the patient in rehabilitation they often try to do everything for the person with a SCI. This also tends to occur when he goes home for visits. When a person with a SCI attempts to help he is often too slow and gets in the way. He is told to relax while the able-bodied cook the meals, wash the dishes, and help him dress. He can’t do things by himself because the environment has not been adapted for him. This can contribute to a feeling of incompetence because he often compares himself with the able-bodied people around him and with the speed at which they do things.

Some people want to do everything for a person with a SCI because it fulfills psychological needs for them. Sometimes they feel guilty because they are able-bodied and the person with a SCI is not and try to compensate by trying to do everything for him. When this happens, the person with a SCI may start believing that he is “special”
and that he deserves special treatment. This can create situations of co-dependency—a situation where one person is providing care and the other person is content in allowing that person to wait on him. Negative affectivity and an environment that promotes dependency may limit a person's ability in emotionally and psychologically adjust to his SCI. There is a fine line between too much help and not enough help. Seldom is the person with a SCI placed in the position where he is in control of the environment and the amount of help he receives.

The look.

Disabled

Now he will spend a few sick years in institutes,
And do what things the rules consider wise,
And take whatever pity they may dole.
Tonight he noticed how the women's eyes
Passed from him to the strong men that were whole.
How cold and late it is.
Why don't they come and put him into bed.
Why don't they come.

Wilfred Owen

This poem expresses the phenomenon of "the look" and conveys the psychological damage to the psyche and self-image that can occur when loved ones and strangers look at you. A person with a SCI is not "looked at" the same way as he was before his accident. He is treated differently. Nothing prepares a person with a newly acquired SCI for the first time someone comes to visit him in intensive care. When I saw visitors reaction to my injury and the way they would look at me it would make me wonder, "Do I really look that bad?" The "look" reinforces and magnifies feelings of being inadequate, incomplete, or less than a person was before his accident. These
feelings of guilt, shame, and inadequacy are reinforced by the “look” (Goffman, 1963; Jones et al., 1984). The “look” lets you know in no uncertain terms that you are different. People don’t interact with us as if we were ordinary human beings. We get treated differently. We get treated like a superhuman because look at all we are doing or you are hurt I don’t think you can do that or you poor thing let me help you and you can’t just get a normal interaction with the person. (JC)

The “look” is a person with a SCI seeing in the eyes of a spouse or significant other the reality of the fact that that person does not want to continue the relationship, but don’t know how to end it. The frequency of the visits of some friends and family members gradually decreases. The visits get shorter and there are more excuses for not coming until many stop coming altogether. My sister never came to visit me in the hospital and my brother seldom came. Fourteen years after my accident my brother told me he didn’t come because he was so hurt by my accident that he didn’t know what to say. These visits or lack of visits contribute to a feeling of being different, less than you were before and contribute to the stigmatisation of a person with a SCI.

The nocebo effect. The Nocebo effect is an acronym for the negative placebo effect, which is inherent in much of modern western medicine (Weil, 1995). The Nocebo effect refers to the hidden and not so hidden messages that are transmitted to the patients in the hospital and rehabilitation settings by doctors and other health care workers. A doctor could dramatically change a person’s view of himself or herself because the doctor is viewed as an authority (Benson, 1996). In fact, doctors are looked on almost as Gods, having all knowledge, and patients, especially those who have just experienced trauma, tend to believe everything a doctor tells them as being true. The doctors, nurses and the other health care workers are mainly concerned with the physical recovery of the patient especially in the early phases of recovery. The doctors and health care workers are afraid
to build false hope so the usual approach is to give the patient and the family the worst

case scenario. This effectively covers doctors from any kind of legal problems and blame
for the patient not getting any return. Early in the recovery process the patient is told to
accept his condition and accept the chair. He is told that he has to let go of the past and
“don’t cry over spilt milk.” He is told that the sooner he accepts the situation and moves
on the sooner he will be able to leave the hospital and get on with life. I was told that I
would have to live in an auxiliary hospital for the rest of my life and that I would need
twenty-four hour a day care. I was told that I would never walk and that I had to accept
the wheelchair. The doctors and the health care workers think that they are doing the right
thing by helping a patient face the reality of the situation and get on with life. The
problem is that what often occurs instead is that hope is destroyed.

Denial is a great motivator. If you stamp that out —that motivation—it might not
be serving the function you want to. You think that once you get rid of this denial
that this guy is suddenly going to get keen and get going on with his life and
doing what he can. It just might have the opposite effect. It’s that denial that is
getting them moving. (JC)

In the rush to get people with SCI out of the hospital and into the community, often
patients are not allowed adequate time to grieve the many losses that have occurred in
such a short time. They have not had time to develop a new set of “I ams” or a new self-
image and way of relating to other people and the environment. People with SCI are often
pathologised and told they have a problem with depression when in fact they are simply
grieving the many losses that have occurred. If they are not experiencing depression or
anger, then they are often diagnosed as being in denial. In fact, they may possess
sufficient coping skills and attributes to deal with the stress or they may be experiencing
the benefits of the “Buffering effect” and are simply hoping to get better.
Hope and denial and grief and depression are often confused. Self-esteem can be eroded by a misdiagnosis of depression causing people with SCI to believe that they have psychological problems as well as being physically disabled. Grief is not a pathology and should not be equated with depression (Fullerton et al., 1981; Howell et al., 1981; Judd et al., 1986). Psychopathology is rare in people with SCI as are “stages of reaction” (Trieschmann, 1988). Each person with a SCI deals differently with trauma on an emotional level (Trieschmann, 1988).

Misdiagnosis of depression. There are many misconceptions that are held by health care workers because they have bought into the myth that people with SCI have considerable pathologies including such things as depression, alienation, anxiety, and lack of self-confidence (Taylor, 1967). Other studies show that rehabilitation workers and other able-bodied people perceive people with SCI differently than they perceive themselves (Albrecht & Higgins, 1977; Caplan, 1983; Lawson, 1976, 1978). There is also the assumption of homogeneity of response to SCI. There is a belief held by many health care workers that all people who experience a SCI must go through an ordered series of emotional states such as denial anger and depression as outlined in the Kubler-Ross model. However, this is not supported by research (Shontz, 1984). Studies by Lawson (1976), Cook (1979), Thompson and Dexter (1980), Howell et al. (1981), Fullerton et al. (1981), and Judd et al. (1986) show that people with SCI react differently to their disability and on average are no more depressed than able-bodied people of the same age.

The doctors and healthcare workers, assuming that they know what it is like to be SCI, often misdiagnose depression because the diagnostic criteria for depression, anxiety, bereavement, and drug toxicity are almost identical (American Psychiatric Association,
If the symptoms of bereavement persist for over two months then a person is diagnosed as being depressed (A.P.A., 1997). The person with a SCI is often under heavy sedation with psychotropic drugs like Morphine, Valium, Demerol, and Baclofin. These powerful drugs can cause a person with a SCI to exhibit symptoms synonymous with depression. Also, at this time the person with a SCI is under tremendous pressure, creating high levels of anxiety about relationships, work, health, and the future. The behaviour of a person with SCI can be misdiagnosed and he can be pathologised as having psychological problems like depression when in fact he is on heavy medication, grieving a series of serious losses, and anxious about an uncertain future.

Charlton and Ferrier (1998) contend that depression can be a wholly physical disorder. They claim that the brain misinterprets sickness and reads it as sadness. They also subscribe to the model of emotion put forward by Damasio (1994), that feelings are the brain's representation of what is going on in the body. The body's automatic response to extreme sickness has evolved so that the body shuts down and withdraws to conserve energy and minimise risk. This produces a physical malaise whereby the person experiences such things as a lack of energy, slowed movement, sleep problems, lack of pleasurable appetites (including sex and food), and lack of concentration. This malaise colours all incoming perceptions and they are stamped in memory as being aversive and negative. When individuals are in the state of malaise and as it continues, remembering events and considering the future summons up the malaise and they are unable to even imagine anything that makes them feel motivated or energetic and they become stuck and have difficulty changing (Damasio, 1994). This downward spiral of seemingly endless pain, bleakness, despair, and depression is referred to in the model as “The Treadmill to
Despair.” The trouble with malaise is that people don’t necessarily know they’ve got it, and they blame themselves for their condition of low performance. Now not only is the person suffering from malaise caused by an extreme physical condition, but they run the risk of being pathologised as having a psychological problem. Healy (1997) contends that depression is more than a disorder of the whole body, it is a disorder of the whole person including the existential and social realms marked by unhappiness and hopelessness.

Until recently, depression was thought of as a chemical imbalance in the brain. The brain was thought to be a stable organ in structure and functioned after birth like a computer. However, researchers are discovering that the adult brain has a high degree of structural plasticity (McEwen, 1999). The brain has the capacity to lose cells and connectors and to produce cells and connectors. The idea that the brain has the capacity for long-lasting and even permanent changes in structure and function is causing a revolution in the way scientists are thinking about depression (McEwen, 1999).

Depression is not completely understood. Depression or its treatment cannot be explained by the concept of a chemical imbalance based on the levels of neurotransmitters (Duman, 1998, 1999). Research by Drevets (1998, 1999) demonstrates that human emotions take shape in neural circuits involving several key areas of the brain including the Pre-frontal cortex, Hippocampus, and Amygdala.

Heim et al. (1997) has also demonstrated that previous stress in youth is critical and coping skills, attributes and spiritual beliefs can influence physiologic-psychological events in the body-mind connection. The body, mind, and spirit are interconnected and act with and upon each other. Some reactions are instinctual, some are learned, some can be willed but all can effect the function of the brain and, in turn, the psychological
response to stress. The secondary losses don’t allow the body time nor needed energy to heal from the original organic stress. This creates a situation where stress becomes chronic if the person does not possess or cannot adopt appropriate coping skills. This continually mounting stress may alter the physical properties of the brain and render the person incapable of coping at that particular time and incapacitate that person because of permanent irreversible changes in the brain (Drevets, 1998, 1999; Duman, 1998). If the stress exceeds the person’s capacity to adequately cope they may begin to feel helpless, vulnerable, shameful, and less than before (Roboff-Bulman, 1992). The Nocebo effect, the “look,” negative affectivity, and misdiagnosis of depression can reinforce and distort a negative self-perception (Brown et al., 1989). If the excessive stress continues over time, negative self-perceptions can be internalised as an enduring negative schemata (Briere, 1996). If this occurs it can cause further stress because the people around him and the person himself thinks that all he has to do is snap out of it when, in fact, there has been a physical change in the brain.

The brain, it has been discovered, has tremendous plasticity. To facilitate the recovery of the normal functioning of the brain, what may be needed is rest and withdrawal from negative experiences in order to revitalise by adopting proper nutrition, exercise, relationships, and recreational activities. This process may include the use of drugs, such as Prozac, that facilitate brain function, and appropriate counselling. Hopefully, medical professionals will take more care with diagnosing depression with traumatic injuries such as SCI because the source of the problem may be other than psychological.
There is a tendency for people with SCI to be misdiagnosed and labelled as being depressed and being in denial when, in fact, they are grieving the loss of the use of their body and all the secondary losses that ensue. During this time they are under the heavy sedation of powerful psychotropic drugs, and are experiencing anxiety about an uncertain future. They are also dealing with the way people “look” at them and the psychosocial stigma of being disabled, imperfect, and different. They are dealing with the negative affectivity of loved ones in environments that limit their ability to exercise freedom of choice and make decisions.

The physical experiences following the accident, in intensive care, and in rehabilitation reinforce the feelings inside people with SCI that they are inadequate, incomplete, and less than they were before the accident. The treatment they receive from the doctors and healthcare workers reinforce feelings of hopelessness and stigmatisation because now, in addition to their physical disability, they now have psychological problems that need to be dealt with. With the diagnosis of depression, people with SCI are given medication in the form of anti-depressants, further complicating long-term adjustment to SCI.

Pre-morbid Personality

The importance of the personality of individuals who acquires a SCI are often overlooked because there is a tendency for able-bodied people to stigmatise them and conclude they are a homogeneous group (Trieschmann 1988). Trieschmann (1988, p. 311) states, “a person’s behaviour or adaptation is a factor of the interaction of the psychosocial, organic, and environmental.” Raferty (1991) suggested that it is the person in interaction with his environment that is the critical feature of all rehabilitation efforts.
The pre-morbid personality determines how people will react to the loss of their physical body and the sudden change in their environment and psychosocial world. Each person experiencing a SCI basically goes through the same lived experiences in rehabilitation. This causes one to wonder, "Why do some individuals with SCI adjust while others do not"? The determining factor in long-term adjustment to SCI appears to be the person's pre-morbid personality, which includes the following components: physical attributes, personal attributes, locus of control, preconceptions of disability, belief structure [religion], coping skills, family relations [childhood experiences], ego maturity, relationships, support systems, age, wealth, and education (Bracken et al., 1981; Dinardo, 1971; Erickson, 1982; Jubala & Brenes, 1988; Katz, 1978; McCann & Pearlman, 1990; Trieschmann, 1988).

Research has shown that people with a SCI tend to adjust better when they possess some or all of the following characteristics:

- young
- well-educated
- mature ego
- strong physique
- financial security
- positive coping skills
- positive personal attributes
- strong nuclear family
- significant relationships
- strong support system
- belief system based on religious, spiritual or altruistic principles outside of oneself (Bracken et al., 1981; Dinardo, 1971; Erickson, 1982; Jubala & Brenes, 1988; Katz, 1978; McCann & Pearlman, 1990; Trieschmann, 1988).

Early experiences of trauma and stress in children have been found to affect their capacity to deal with stress as adults (Heim et al., 1997). The ability to cope with stress and depression may also have a biological basis (Davidson et al., 1999; Drevets &
Raichle, 1998; Drevets, 1999; Duman, 1998). Some people have a greater physiological capacity to withstand a stressful situation and not be traumatised by it. The only tools that people can bring with them to help them in the process of adjustment to the trauma of SCI are the pre-morbid coping skills, attributes, and personal resources that they developed in their childhood (Alexander, et al., 1992; Briere, 1996).

**Filter of Meaning**

The Filter of Meaning is a pivotal concept in understanding “World Collapse” and the psychological issues that stem from the lived experience of a SCI. There is evidence that a peoples’ ability to cope prior to their accident is predictive of their ability to cope and adjust after a SCI (Bracken et al., 1981; Katz, et al., 1978; Young, et al., 1982). There also appears to be no correlation between level of break or degree of impairment and long-term adjustment to SCI and it did not seem to matter about relationships (Brenes et al., 1986; Kennedy et al., 1995; Knight, 1989; Shontz, 1984). The pre-morbid personality acts as a filter, determining the significance and the meaning of the lived experience of a SCI (Oliver, 1988). The filtering effect of the pre-morbid personality determines how individuals with SCI react and behave as they respond to the demands of the organic biological, environmental, and psychosocial components of their rehabilitation as discussed by Trieschmann (1988).

**Psychological Issues**

The psychological issues that present themselves in the rehabilitation setting are determined by the filtering effect of the pre-morbid personality. When the pre-morbid coping skills and the personal resources of individuals experiencing a SCI are exceeded
they experience a “World Collapse” which, if intense enough, can cause a shift in the person’s autonomic nervous system.

**Buffering effect.** The “Buffering effect” is the body’s unconscious automatic method of protecting itself from experiencing an affect overload. In 1966, Hohmann reported that people with SCI, especially high lesion quadriplegics, demonstrated a marked reduction in the need for sexual stimulation and displayed less anger while exhibiting an increase in affection and sentimentality. Hohmann (1966) speculated that there was a disruption to the autonomic nervous system (ANS) that decreased negative emotional feelings thereby decreasing depression in individuals who experienced a SCI. Horowitz (1986) and Damasio (1994) substantiated Hohmann’s findings and Herrick (1991) referred to this phenomenon as a “Buffering effect.” Horowitz (1986) and Damasio (1994) claim that when a person’s ability to cope is exceeded by the pressures and stress exerted by the environment that the trauma can trigger changes in the ANS that can prevent the person from experiencing negative emotions.

**Frozen in time.** Horowitz (1986) and Damasio (1994) theorise that when a persons’ coping skills are overwhelmed, negative emotions or affect, instead of being experienced are stored in the brain and in the body remaining dormant, frozen in time, until a future event triggers their release. When the affect is released, the emotions are as raw and fresh as when they were first experienced and stored by the “Buffering effect” (Damasio, 1994; Horowitz, 1986)

**Denial.** Denial is a cognitive process in which the person re-frames and reorganises the information he receives and puts a positive spin on it so that he can maintain hope. Denial is an important tool that allows individuals with a SCI time to
readjust cognitively to the new organic, environmental, and psychosocial, situation they find themselves in (Caplan, 1987). Denial is a way of avoiding the fact that a person with a SCI will not get any return or walk again. Denial allows time for him to develop the appropriate coping skills to deal cognitively with this harsh reality.

At that time I was convinced I was going to make it back and that is what I had to look forward to was that I was going to get back to standing on my feet. Not really realising that was going to be impossible from then on. (GG)

My self-perception did not change the moment I broke my neck and it took many years to mould a new self-perception and I think that is how denial can be helpful until you are ready to accept this new JC you held on to the old JC. (JC)

Caplan (1987) pointed out that denial was a useful adaptation initially but that eventually people need to let go of their denial in order to adjust.

Denial is a valuable mechanism that protects the patient in the initial stages of injury. In the normal run of events, denial gradually reduces as the patient slowly, in his or her own time, takes on the implications of the injury. There may be short periods of depressed moods, but normally with the help and support of the team (who emphasise positive coping) they are short. Problems arise when denial persists beyond its usefulness. (Caplan, 1987, p. 5)

The “Buffering effect” acts unconsciously and automatically. Denial is a conscious re-framing of the available information used by people to put a positive spin on their predicament no matter how precarious, to enable them to maintain hope. The “Buffering effect” and denial act in concert to suspend affect from consciousness, keeping it “Frozen in time.” The affect that is stored in the sub-conscious, when triggered and released, will be perceived as if it was brand new and the traumatic experience had just occurred. The issues and the affect that are stored, “Frozen in time” from traumatic events like a SCI are huge and there is a tendency for everyone involved to avoid dealing with these issues and emotional memories until absolutely necessary.
Psychological issues that occur in rehabilitation. The pre-morbid personality acts as a filter to interpret and give meaning to a person’s experience of SCI. The experience is composed of organic, environmental, and psychosocial components that interact with one another simultaneously and in parallel (Trieschmann, 1988). The loss of the use of the body and bodily functions are compounded by environmental and psychosocial factors experienced in the rehabilitation process and put tremendous stress on the persons coping capacities. Some of the issues that the person with a SCI may have to process and deal with are:

- negative self talk
- feelings of self as less or inadequate
- feelings of being incomplete
- feelings of shame or guilt
- feelings of anger at self, God, or others
- anxiety attacks because of paralysis
- loss of feelings of self-worth
- loss of personal boundaries and identity
- loss of hope for a future
- loss of the meaning for living

Signs of an inability to process psychological issues. When individuals with a SCI experience World Collapse often their ability to cope with their new situation is exceeded and they display inappropriate behaviour. These behaviours, to an objective observer, appear inappropriate but they can be explained by the fact that individuals in the midst of a World Collapse are simply attempting to somehow cope and adapt to a situation that they cannot and do not want to deal with. One of the first indicators of maladjustment is inappropriate overt expressions of emotion, including increased sentimentality and anger, which are often triggered by something as minor as a sad movie or by simply dropping something on the floor and not being able to get it. Another sign that a person with a SCI is not adjusting well is self-mutilation. An example of this was when JC pounded on his
legs when they started to spasm. Other examples of self-mutilation or self-neglect are not taking medications on time, not lifting their buttocks every twenty minutes, not drinking enough water, and not wearing proper footwear in winter. Often individuals with SCI who are not adjusting well to their new body image will make inappropriate sexual innuendoes and gestures. At first many people with SCI feel the necessity to talk about their accident and how they feel with everyone they meet. They may also experience phobias, hallucinations, and nightmares and extreme anxiety about an uncertain future. Avoidance is another sign that individuals are not adjusting well to their SCI. They often avoid anything that may represent a threat to them to the extent that they withdraw and isolate themselves. Individuals who cannot cope with their current situation often attempt to escape from their problems with obsessive compulsive behaviour in the form of drugs, alcohol, and sex but escape can also be found through work, sports, or school.

The display of any of these behaviours can act as a signal that these individuals do not have the necessary coping skills, attributes, or personal resources to adjust to the trauma of SCI.

**Psychological implications of an inability to cope.** If people's attributes, coping skills, and personal resources are not adequate, then they will experience a disintegration of their ego, self-esteem, self-worth and self-confidence. They will lose their self-identity and not be able to maintain personal boundaries. They will experience fragmentation (Hamilton, 1988), dissociation (Briere, 1992), and they may lose all hope for a future and a meaning for living. There is also a tendency for individuals with a SCI to feel inadequate, loathsome, and that they deserve to be treated poorly (Roboff-Bulman, 1992; Jehn, 1988; Peterson & Selegman, 1989). When people with SCI become overwhelmed
and they feel like life as they knew it is completely destroyed and there appears to be no
hope for a favourable reconciliation of reality, they may experience a descent into what
Welwood (1982) describes as World Collapse.

**Point of world collapse.** The point of World Collapse is a difficult concept to
explain unless one has experienced it. Welwood (1982) explained that up until this
moment, life seemed normal when suddenly everything around us seems to collapse into
a void of transitory nothingness in which all our attempts to grasp onto something solid
seems doomed forever. Nishitani (1982) explained that in this moment “a gaping abyss
opens at the very ground on which one stands. In the face of this abyss, not one of all the
things that had made up the stuff of life until then is of any use” (p. 3). From the moment
people experience a SCI their lives are thrown into disequilibrium. They must contend
with losing the use of their bodies and interacting with time and space differently. They
are placed in a new environment over which they have no control. They are faced with
losing and renegotiating relationships.

The moment of World Collapse is felt suddenly, in an instance, at all levels of
existence. This pervasive, overwhelming feeling of utter emptiness is so intense and
terrifying that it seems to trigger an instant response in order for the person to survive. It
appears that, in that split second, the pre-morbid personality is crystallised and the person
makes a decision to survive, losses hope, or somehow maintains hope. Each participant
could clearly remember this exact moment. Some of the participants experienced more
than one World Collapse. World Collapse could happen at any time from the time of the
accident to many years later.

I can consciously remember lying in the hospital a couple of weeks after my
injury after I finally got out of intensive care and thinking you know the world
owes me and I thought about it for another second and thought, “If I died right now the world wouldn’t care. If I want to make something of my life I have to choose to do that at this point and time because the world doesn’t owe me anything.” (LN)

I felt tremendous guilt at that point. ---Anyways the point is—I’m there—I knew what happened to me and I had a pretty good idea and then I started to hate life a little bit and they are really concerned because I didn’t realise just how bad the damage was. (BA)

World Collapse appears to be a necessary first step in the process of adjustment to SCI. If people with SCI retreat from this moment of World Collapse and attempt to recapture the life that they had before their accident, they will always remain a diminished self. People with SCI cannot reclaim self because it is a physical impossibility. Instead, they must attempt to transcend self and embrace a new way of Being-in-the-world. This requires a person to embrace this moment with what Yalom (1980) and Heidegger (1962) called “resoluteness” or as Tillich (1952) proposed “the courage to be.” TB and BA referred to this as desire. The only way to endure the experience of World Collapse is to embrace the concept of hope with resoluteness and courage and step-by-step create a new definition of self.

Crystallisation. There is no way for people to adequately prepare for the shock and trauma of a SCI. Even with the aid of the Buffering effect and denial, a person’s coping capacity and personal resources eventually become overwhelmed and he will experience World Collapse. When this happens, it appears that people experiencing SCI resort to the coping skills and resources that were most effective for them before their accident.

I think an injury can cause a certain trait to become more pronounced if it is something that the individual has control of because what happens with an injury especially a traumatic injury, is all of a sudden, you feel you have no control. So if there is an area of your life that you think you can still control whether it’s your
religion, or it’s your personality, your attitude, whatever, if you feel you can still control, you sometimes have a tendency to draw into it more. So it becomes more pronounced than it was. (GG)

You see what is coming out now is always inside of me, but it was the conditions and the accident and stuff and the circumstances of what happened that made me bring this side of me out. The need to survive accelerates it quickly. But the thing is that it was always there but you never used it because you never had to. Now you have to use it to survive, before everything just fell into place. You could use force if nothing else to make it fall into place if you are a very physical person. (TB)

The participants of this research each resorted to their dominant pre-morbid coping skills in an attempt to survive and deal with the trauma in the best way they could regardless of how ineffective these methods were.

**Entry into the community.** Eventually the rehabilitation phase ends and individuals with a SCI are released from the rehabilitation centre into the community. This is a stressful event because no longer is the environment customised for them. They are faced with the prospect of existing in a hostile world facing all of the challenges of being SCI including secondary loses, financial difficulties, relationships, time, social stigma, and architectural barriers. Their pre-morbid attributes, coping skills and personal resources manifest themselves at this time, influencing the decisions they make and the pathway they choose to adjust to their SCI.

**Long-Term Adjustment to the Trauma of SCI**

TB stated, “Adjustment is a lifetime ambition.” Dealing with a SCI is a lifelong process. No one ever completely “adjusts” to a SCI because there is no endpoint where all is well and conflicts between desires and abilities are resolved (Cook, 1979). Corbett (1980) added that dealing with a SCI is a lifelong battle, a monumental inconvenience.

This research theorises that adjustment to SCI is not a linear process but rather a
dynamic, cyclical process involving three pathways namely: Survival; Treadmill to despair; and Hope: The healing path. To facilitate the understanding of this grounded theory it will be discussed in three parts, each accompanied by a model to be referred to while the text is being read. The model for Survival is presented as Figure 2, The Treadmill to Despair is presented as Figure 3, and Hope: The Healing Path is presented as Figure 4.

There seems to be no correlation between level of break and severity of impairment to a person's adjustment to SCI (Kennedy, 1995). There is evidence that time does not heal because studies have shown that adjustment, based on scores of depression, has actually declined after five and ten years as compared to baseline scores taken the first year after the accident.

There also is little evidence demonstrating that interventions undertaken during intensive care, rehabilitation, or during the first year of release into the community have any correlation with long-term adjustment (Craig et al., 1990). This reinforces the importance of the pre-morbid personality of the person experiencing the SCI because individuals bring their own special combination of physical, spiritual and psychological attributes; coping skills; relationships; family; age; wealth; and education into the experience. This means that even though two people are both C-5 quadriplegics, their level of impairment and their ability to cope and adjust to their SCI will be different because they are unique. They will experience the environment differently because of differences they have in their physical impairment and other personal resources they possess. Their pre-morbid personality acts as a filter that gives weight and meaning to their experience of SCI.
When they experience World collapse, it is theorised, people with SCI resort to their pre-morbid coping skills and self-resources. These skills often prove inadequate and the person is overwhelmed and unable to cope with the added stress of a SCI. When this occurs the ANS responds by automatically using a buffering effect to store emotional affect, which eases the impact of the trauma of SCI.

The recovery and long-term adjustment to the trauma of SCI injury is not a linear process. However, a common myth shared by many people with SCI and those who work with them and counsel them is that there should be a slow and steady progression over time towards adjustment and an improved quality of life. This is not necessarily the case because there appears to be a re-experiencing of World Collapse that surfaces when a person with a SCI is faced with a new or different barrier or life situation that they are unable to deal with. The coping skills and attributes, which were adequate during the first few years of rehabilitation, suddenly prove inadequate and the person is overwhelmed with feelings and emotions that they thought they had already dealt with. This phenomenon occurs when the person with a SCI has an experience, which triggers the affect that had been stored, “Frozen in time” in the sub-conscious. The triggering event could be an extremely negative or positive event like witnessing a death, being seriously injured again, or being promoted at work. The event triggers affect, which has been frozen in time, that is now brought to consciousness and may cause a person severe emotional distress, requiring professional intervention.

Crossroads: Decision Time

When people with SCI experience World Collapse there are three basic pathways, which they may chose to follow. They may chose to survive and live in the here and now;
or they may give up hope and chose to commit suicide or escape to Fantasyland and the Treadmill to despair, or they may embrace Hope and embark a journey of growth, progression and self-fulfilment. Each time people with a SCI “Defrost Unfinished Business” the situation has changed and they must, once again, decide which path they will chose.

Survival

The model demonstrating the pathway of survival is presented as figure 2. During intensive care and the rehabilitation phase at the hospital individuals with a SCI struggle to simply survive. They resort to their pre-morbid personal attributes, self-resources, and coping skills. They tend to cling to those personal attributes and coping skills that worked best for them before their accident. This creates a crystallising effect where these behaviours tend to be magnified. For example, people may become extremely religious and spiritual while others, totally disregard religion and deny the existence of God. Some people may want complete silence and need to be alone while others need to have the TV on or have people with them all the time. Some people may daydream, or read while others fill their time with music, working out, or visiting. Many times these activities are simply a way of avoiding dealing with the psychological impact of the losses they have sustained in such a short period of time. It is much easier to live in the here and now and avoid thinking about the past and what they have lost by focusing on what they are doing or going to do.

Survival is initially a healthy adaptation because it gives individuals with SCI time to physically mend and cognitively absorb the reality of their situation. The Buffering effect and denial prevent them from being completely overwhelmed by all the
losses they have recently sustained. Too often it is convenient and safe for people who have experienced the trauma of a SCI to remain in survival mode after they leave the rehabilitation centre. They create a situation, using their pre-morbid coping skills, where they feel safe and competent because they have found a way to survive and cope in the here and now. However, these coping skills often are only effective in the short-term.

An example of this could be spending all of one's time playing wheelchair sports, or attending University and getting a degree. So much time and energy is spent obtaining immediate goals that time cannot be spent on processing issues related to their accident, the secondary losses created by the accident, and the subsequent affect that has been stored in their sub-conscious Frozen in time by the Buffering effect. The person with a SCI may get enough recognition and self-fulfilment from accomplishments in wheelchair sports, relationships, or school that they don't worry about deeper issues.

An important consideration about being on the pathway to survival is that many coping skills only provide a temporary respite from the trauma of SCI. Eventually, situations arise in which individuals must leave their comfort zone because of new relationships, barriers, or life situations. Suddenly school is over, their mother dies, or they can't participate in wheelchair sports any longer or some other event occurs that triggers the affect which, until now, had been frozen in time, hidden from consciousness.

The coping skills, attributes and self-resources that once were sufficient are no longer adequate and new ways of coping and adjusting must now be found. The negative coping skills, attributes, self-resources, and ways of communicating and maintaining relationships that are prevalent in survival will be included with the positive coping skills
and attributes, essential for long-term adjustment to SCI in the discussion of Hope: The healing path.

When individuals with SCI are simply surviving they may experience an obstacle or barrier that they cannot cope with, triggering affect that until that moment was unavailable to consciousness. This creates a disequilibrium, forcing them to process the stored affect in an attempt to re-establish homeostasis. The process of bringing the stored affect to consciousness is pivotal a concept in this study and is referred to as “Defrosting Unfinished Business.” A detailed explanation of this process is discussed in the Implication for Counselling section of this discussion and therefore will not be explored further at this time.

Individuals with a SCI may be overwhelmed and unable cope because of this newly released affect, created by an intrusive triggering event. Often this causes them to lose hope, initiating a process identified by TB as the “Treadmill to Hell.” In this study the process of losing hope is described as the “Treadmill to Despair.”

The Treadmill to Despair

The model illustrating the pathway of “The Treadmill to Despair” is presented as Figure 3. When individuals experience World Collapse after a SCI they have a tendency to revert to their pre-morbid coping skills. Nothing in their previous life can prepare them for this. Coping mechanisms that once worked in the short term may not work over time. They often finds themselves in a position in which they cannot appropriately adapt to their new environment, relationships, barriers, or the ongoing contingencies of life. They lose hope because they find themselves in a rut and cannot imagine or dream of an alternative way of being and doing. Even if they can picture a goal or a dream, pathways
to accomplish these goals and be successful may be beyond their ability to obtain and therefore are not a cognitive reality to them.

When a person with a SCI loses hope and becomes depressed suicide is often considered. Suicide rates for people with SCI vary from 14% to as high as 28% depending on the study with an average suicide rate of approximately 18% or five times the rate for the general population (De Vivo et al., 1991). Suicides for people with SCI do not occur in the intensive care or rehabilitation settings but after the person with a SCI has been released into the community. Many of the suicides occur several years after release from the hospital. Surprisingly, the highest incidence of suicide is in high functioning partial lesion paraplegics, many of them being able to walk with assistive devices. The lowest suicide rates in SCI males are in complete lesion, low functioning quadriplegics (De Vivo et al., 1991). There are also studies that demonstrate that SCI males are no more depressed than the able-bodied population and yet the suicide rate for SCI males is five to seven times higher than the able-bodied population. How can these discrepancies be explained?

In intensive care, the rehabilitation setting, and during the first year of community living people with SCI are often in survival mode using their pre-morbid coping skills. The “buffering effect” and denial have allowed them to avoid dealing with much of the affect. Initially their coping skills combined with the “buffering effect and denial enable them to function in a personally acceptable and adequate fashion. In fact many of the people with SCI honestly believe that they if they work hard they will be able to make a complete recovery.
If individuals with a SCI are measured for depression or adjustment at this time, it is likely that their scores will fall within the range of normalcy because they still have hope of a complete recovery. In reality, few people with SCI generate significant additional return after the first six months. Individuals with a SCI who experience a complete lesion realise very early in their injury that they are not going to walk again. Hope of additional recovery is rapidly extinguished during the first year because they get no additional sensation or movement of any consequence. The people who experience a tremendous amount of return during the first six months often get sensation or movement and sometimes some of both. This creates a situation in which they think they will continue to improve until they recover completely. This does happen occasionally. However, in the majority of cases, recovery stops somewhere short of complete. The sensations for pain can be complete but the nerves controlling movement can be incomplete or vise-versa. The damage to the nervous system is seldom symmetrical and antagonistic muscles usually no longer balance each other. This creates contractures that cause twisting and deformation of the spine and joints eventually leading to arthritis and pain. If the difference in the antagonistic muscles is great enough the deformation and pain can be excruciating.

Individuals with SCI who were injured in the lumbar area may be able to walk and function normally except that they may be completely impotent because the nerves controlling sexual function are in the lumbar area and have been damaged. In contrast individuals who sustain a C-7 SCI may have sufficient sexual capabilities to achieve erection and ejaculation because the nerves controlling sexual function have not been damaged and can be triggered by fantasy or stimulation.
Partial lesion paraplegics would appear on the surface to have a better chance to be well adjusted than quadriplegics. However, they may be experiencing extreme pain, and be impotent. They also do not fit well into the able-bodied world or the disabled world because they are in the grey area in-between and seem to fall in-between the cracks. People who experience complete lesion quadriplegia realise early in their injury that their life depends on co-operating with other people. Many of the people who experience partial lesions and are high functioning fall into the trap of attempting to do everything on their own and isolate themselves from others in an attempt to show the world they are able to be independent. The pain and the isolation often drive these high functioning people with partial lesion SCI into the Treadmill to Despair where they commit suicide or experience a premature death due to self-neglect and the misuse of drugs and alcohol.

The lower suicide rate among low functioning quadriplegics can be explained by the fact that they cannot survive without daily help from other people. This forces them to learn how to communicate. They are forced at a relatively early stage in their recovery process to recognise and admit to themselves that they need help and they need to change in order to survive. They also have daily contact with their health care suppliers. It is impossible for them to withdraw and isolate themselves because they are forced to adapt and change. They are forced from the beginning of their injury to shift their consciousness and adopt new coping skills and attributes.

The abilities of full lesion paraplegics do not change much after the first few months. Unlike the quadriplegics, they can live independently. If they get depressed, they can withdraw and isolate themselves. The quadriplegics cannot hide their sadness and
their healthcare workers can help them work through issues. Many paraplegics are caught up in the myth of proving they can do it on their own and be independent believing that getting psychological help is a sign of weakness.

Once individuals with SCI are overwhelmed, it is difficult for them to get out of the rut of depression found in the Treadmill to Despair. The high functioning quadriplegics and paraplegics are physically capable of maintaining an almost normal lifestyle and live independently. This, however, is where the problem lies because they live in a grey world that is not quite in the able-bodied or the disabled world. The emergence to consciousness of issues that were stored in the sub-conscious may be delayed for several years because of the buffering effect. There is a tendency for individuals with partial paralyses to hold on to the dream of a complete recovery and their pre-morbid personalities and coping skills and attempt to recover and reassume their previous identity. They place themselves in a frustrating position because they do not accept their impairments or disabilities and yet they are not completely accepted into the able-bodied world. They are therefore stigmatised and not completely accepted in either the disabled or able-bodied communities. They are usually in a lot of pain because of arthritis, but can successfully live on their own. The pain, and not quite fitting in to the able-bodied or disabled communities, can perhaps explain why the suicide rates are higher for partial lesion paraplegics and quadriplegics than their complete lesion counterparts.

After successfully coping with a SCI for years an event like a death or a new barrier may trigger the release of stored affect and a new problem is brought to consciousness. The person is then forced to Defrost Unfinished Business that had been
stored in the sub-conscious, Frozen in time. If he is unwilling or unable to process this new affect, brought to consciousness, there is a tendency to try to escape either through suicide or by entering into Fantasyland.

_Fantasyland_. When individuals with SCI become depressed, there is a tendency to withdraw and isolate themselves, escaping from the real world. People who are not coping well with psychological issues may also display maladaptive behaviours, like obsessive compulsive behaviours, self-mutilation and overt expressions of emotions. People with SCI who are in escape mode can end up watching TV excessively, abusing alcohol and illegal drugs, be consumed with sex and pornography, or overindulging in a hobby or a sport. They may avoid responsibilities or do things that physically or psychologically put them at risk. They may talk and sexually act out inappropriately in public. They may display tremendous mood swings and overt expressions of emotions. When individuals with SCI are in Fantasyland, reality is distorted especially if drugs are involved. Prescription drugs mixed with street drugs can create a tremendous distortion of reality. There is usually an erosion of self-confidence and self-esteem whereby individuals reject themselves as worthwhile and visualise themselves as less than before or incomplete. This process can lead to a person fragmenting and experiencing dissociation (Briere, 1992; Hamilton, 1988; Van der Volk, & Fisler, 1990). Their ego and self-esteem are destroyed and they lose hope. They believe that things will never change, that things will never improve, and that they will feel this way forever.

These feelings may also lead to what Nechemkis and Groot (1980) identified as indirect self-destructive behaviour. When individuals with SCI feel depressed and try to escape with drugs and alcohol, there is a tendency for them to neglect their personal care.
They forget or are unable to lift themselves every 20 minutes or turn every two hours when sleeping. This results in bedsores or dicubitus ulcers. To complicate matters further, these sores are not discovered for many weeks because they are out of sight and the pain cannot be felt. Dicubitus ulcers can become infected with powerful and deadly bacteria, which can be resistant to all forms of medication. Often bedsores require a minimum of a month and possibly as long as several months in the hospital to heal. This can create a whole new realm of problems for individuals with SCI, from losing a job to destroying relationships just by not paying attention to their skin on their buttocks or other small cuts and scrapes. When people with a SCI don’t care any more, when they lose hope, they may not catheterise themselves correctly or drink enough water, which leads to bladder infections and could eventually result in renal failure. They may not eat properly, do their bowel routines properly, practice proper hygiene, or dress appropriately, which can result in infections and pneumonia (MacLeod, 1988).

Any of these medical conditions further exacerbates the downward spiral of depression and the sense of hopelessness deepens. There are many men with SCI who die prematurely from complications due to bacterial infection, renal failure, pneumonia, and drug overdose that cannot be included as suicides but are caused by neglect. It is estimated that as many as 34% of the men with SCI die a premature death (MacLeod, 1988). Premature deaths for people with SCI are unnecessary and could be prevented with proper self-care practices. Premature deaths occur because they have given up hope and do not consider it worth the effort to take proper care of themselves. Many people with SCI die from infections and cancers and it appears that their immune systems...
become exhausted because of the constant stress created by self-neglect. MacLeod (1988) stated:

   The psychiatric equivalent of immunological exhaustion in spinal injured patients may be the phenomenon of existential self-neglect. (p. 348)

If people with SCI are no more depressed or any less well-adjusted then why are so many dying unnecessarily and prematurely? It may be that they are unable or unwilling to learn and adopt the appropriate attributes and coping skills necessary for successful adaptation to SCI.

Rehabilitation programs focus mainly on the biological, medical, and physical problems of SCI and do not help the person with a SCI adequately deal with the psychological aspects of recovery (Bracken et al., 1981; Craig et al., 1990; Trieschmann, 1988). Seldom is help given to a person with a SCI in the areas of existential or transpersonal psychotherapy. As BA stated:

   They know the physiological aspects and OK the bones healed, the tissues healed, and the scars healed and blah, blah, blah, but they don’t deal with the psychological aspects and nobody really did.

The key issues of meaninglessness, isolation, freedom, and death are seldom addressed. Spiritual matters are virtually ignored while the focus is on the physical and medical problems. Once a person is on the treadmill of self-destruction, it is difficult to break the downward spiral of depression because often they have crystallised a negative cognitive schema of being diminished and incomplete (Briere, 1996). To escape the Treadmill to Despair, a person must somehow become aware of the reality of their situation and their behaviour.

Awareness can be caused by an event that triggers such a powerful response that issues that had been Frozen in time, unavailable to consciousness, are suddenly brought
to consciousness. This event could be the death of a loved one or a friend taking them to
a wheelchair basketball game. It could be a divorce or something as simple as looking out
the window and realising that they hadn’t left the house for over two weeks and that life
was passing them by. Yalom (1980) and Perls (1976) maintain that awareness of a
problem, in and of itself, is often enough to solve the problem. The trauma of SCI is so
intense that many of the issues and affect surrounding the accident are initially
unavailable to consciousness. Awareness of the fact that the disequilibrium, intense
emotions, and negative acting out, that individuals with a SCI are experiencing, are
linked to unprocessed, Unfinished Business surrounding the accident can be the first step
in re-establishing hope for individuals with SCI. This opens the door to therapeutic
intervention, by a knowledgeable counsellor, and hope.

Hope: The Healing Path

The model illustrating Hope: the healing path is presented as Figure 4 and is
designed to be used with the text to improve visualisation of this process. The key
component to long-term adjustment to SCI is hope. Hope has two components that act
together in harmony. If either component is missing, then a person will not be able to
embrace hope.

The first component of hope is agency in the form of a deep and abiding will to
live and to succeed (Elliott et al., 1991; Snyder, 1989; Snyder, 1991). The will to live and
succeed is derived from personal attributes that are ingrained into the personalities of
individuals with SCI before their accident. It is difficult for individuals to change their
attributes because they are formed during their childhood and young adult life. Desire is
the primary attribute that acts as a catalyst to enhance other personal attributes that enables individuals to successfully adapt to their SCI.

The second component to hope is that individuals with a SCI must be able to believe cognitively that there is a pathway available for them to successfully accomplish their goals (Elliott et al., 1991; Snyder, 1989; Snyder, 1991). If individuals with a SCI doubt that they have the physical or intellectual abilities to succeed or if barriers such as money, equipment, environment, or prejudice seem to preclude them accomplishing their goal then they will lose hope. To help establish pathways for success a person with a SCI can adopt positive coping skills to create pathways that can become a cognitive reality. However, without a deep and abiding belief that what they are doing will make a difference in the long-term, individuals will lose hope and slide into a negative cycle of despair.

**Coping and adjusting.** The importance of better understanding of the effects of SCI on psychological adjustment could perhaps be considered an essential ingredient in the rehabilitation of a person with SCI (Craig et al., 1990). The pre-morbid personality of a person is of prime importance for predicting how someone will cope when experiencing a SCI (Bracken et al., 1981). When a person suffers a severe trauma like SCI, there can be a complete disintegration of a person's self-identity and a destruction of a person's ego (Briere, 1996; Hamilton, 1988; Van der Volk & Fisler, 1990). Erickson (1982) stated that a fully developed and mature ego could cope with adversity much better than an immature ego. The total World Collapse experienced by some individuals with SCI injury can be so overwhelming that a person loses the ability to cope. Selye (1976) maintains that a person has only so many resources at his or her disposal for coping.
People with SCI are overwhelmed because of insufficient resources needed to cope with the severe trauma of SCI. The experience of World Collapse and the destruction of a their self-identity and ego can push individuals SCI beyond their ability to cope, creating a situation which forces them to adopting maladaptive behaviours in order to survive. Examples of these coping behaviours are wish-fulfilment; fantasy, escape into drugs, sex, alcohol, TV, music, sports; self blame; threat minimisation; and overt emotional expression (Buckelew et al., 1990).

Coping and adjustment is a process that can be affected by many factors. Heinemann, Bulka and Smetak (1988) stated that adaptation following SCI is a developmental process and that intervention may therefore be quite different during acute versus post-acute recovery. It is impossible to isolate and separate an individuals developmental levels, situational factors, social supports and the perceived stress in order to determine what coping styles will work best with which people with SCI to help them achieve long-term adjustment (Heinemann et al., 1988; Lazarus & Folkman, 1984; Rosenteil & Roth, 1981; Silver & Wortman, 1980; Taylor, 1983). Hansen et al. (1993) claimed that coping strategies at early stages of recovery are not predictive of long-term adjustment and that there is a need for coping styles to change over time. As the needs of a person with a SCI changes so does the coping style (Shultz & Decker, 1985).

Winneman et al. (1994) stated:

The kinds of coping behaviours used to manage situations encountered by healthy individuals (Folkman et al., 1986) or those newly diagnosed with cancer (Mishel & Sorenson, 1993) are different from behaviours used by community populations with long term chronic conditions. (p. 272)
This statement is consistent with the findings of Folkman and Lazarus (1988) that coping is situationally specific and based on the context in which the person-environmental transaction occurs.

Coping skills. When people experience a SCI there is a tendency for them to shift into a survival mode and use inappropriate coping skills like: emotional display; threat minimisation; fantasy; and wish fulfilment (Buckelew et al., 1990; Craig et al., 1990; Elliott et al., 1987). The inappropriate displays of anger and sentimentality can be traced to affect that has not been released, stemming from Unfinished Business. Events often trigger the release of these pent-up emotions without the person with a SCI realising the true source of this rage. The person with a SCI may also exhibit various creative avoidance behaviours, which minimise the threat of the re-experiencing of hurtful emotions that are linked to Unfinished Business created by the trauma of the accident. People with SCI who are in a survival mode may rely on fantasy and wish fulfilment to succeed instead of setting goals and taking direct action. An example of this could be that a person with a SCI could purchase ten Lotto 649 tickets each week, convinced that they will win the lottery, instead of getting an education or a job. Or they may believe that a beautiful woman will marry them and take care of them so they don’t need to worry about self-care.

People who adjusted well to SCI in cross-sectional studies conducted at 10 and 15 years post injury exhibited the following positive coping skills.

- Desire for information
- Cognitive re-structuring
- Goal setting
- Willingness to change
- Direct action
- Emotional regulation
- Re-defining success
  (Buckelew et al., 1990; Craig et al., 1990; Elliott et al., 1987)

The people with SCI who were well adjusted were constantly attempting to gain more information by reading books and pamphlets about SCI. They asked questions about their drugs and treatment and tried to find out how their injury would affect their ability to have sexual relations. They constantly asked their doctors, nurses, and everyone they could to help them figure out what was happening and what they had to do to get better. The health care community seems to think that it would be detrimental to the person with the SCI to have all the information. For example, in intensive care few patients know that spinal shock can last up to approximately three months. At the end of the spinal shock, it is possible for a person to experience return. Patients are told that they will never walk again and that they need to accept their chair. The simple truth of the matter is that health care professionals don’t know what will ultimately happen. Why not be honest? Why extinguish hope especially in the first few weeks or months? With the proper information a person with a SCI can make decisions based on facts instead of emotions and myths.

One of the most difficult things for individuals with SCI is cognitive restructuring. This process involves first, evaluating the physical, biological-medical, and the psychosocial environments that they must now live in and, then, determining what they need to do to be successful in each of these environments. They must take a realistic inventory and evaluation of their assets and liabilities. This does not necessarily mean that goals need to be eliminated, but that time-lines and ways and means of achieving these goals may need to be re-thought. This is where the attributes of creativity, imagination, determination and perseverance can contribute to a coping skill. Several of
the participants mentioned that there were few problems that they could not somehow
find a solution for or way around.

One of the biggest barriers to adjustment is not being able to change. Individuals
with SCI interact with time and space differently from the way they did before their
accident. This means that all the tasks of daily living and all the interactions with people
will have to be done differently. Their bodies are different. Everything is different. The
problem is that people don’t want to change. However, they must change in order to cope
and adjust to their SCI and maximise their remaining abilities and potential.

A common problem is that many people with SCI define success in pre-accident
or able-bodied terms. Happiness in North American culture is often equated with having
a good job, making a lot of money, being in a meaningful relationship with a beautiful
woman, and being strong and athletic. Using these criteria, it is extremely difficult for a
person with a SCI to be happy.

The participants in the current research study discussed re-defining success. They
talked about not comparing themselves with other people. They talked about the
importance of being realistic about their physical and cognitive abilities and having
realistic expectations about what they could do with those abilities. They defined success
as, “doing the best you can with what you have,” instead of adhering to an external scale
of success based on an able-bodied standard. People with SCI often don’t give
themselves enough credit for the things they do accomplish. Instead, they judge
themselves on the basis of what they don’t accomplish, which often, in their eyes, means
failure.
Standards of success evolve during the life of a person with a SCI, for example, during rehabilitation success may be as simple as transferring from a bed to a wheelchair. Later, success might be completing a marathon in a wheelchair, then winning a marathon. Later in the life-course of the person with the SCI, due to injuries or ageing, being able to transfer out of bed may once again represent success. It is imperative that individuals with SCI re-define success based on a realistic evaluation of what their potential and abilities are at this time and situation.

Goal setting is critical for successful adjustment to SCI. However, knowing what goals should be selected to achieve success is difficult and often needs the assistance of a counsellor. I asked BA how he thought a counsellor could help a person with a SCI set goals. His answer was brilliant.

I would have them paint a picture. Create a picture in great detail of their perfect dream. You would make certain that that was what they really wanted and would make them happy. For example their dream might be to own a big house in the country and have a beautiful wife and lots of money. You would have them describe everything in great detail. What does the house look like? How are you going to make your money? Then, help the person create a plan for accomplishing these larger goals by breaking them into smaller goals, then those goals into smaller goals. (BA)

He stressed that the smaller goals had to be doable and progressive so that each goal once accomplished would add momentum and incentive for accomplishing the main goal.

Once the goals have been defined and set, the next thing that is required is direct action. Once again, desire is needed. Where does the will to accomplish these goals come from? Where does the person with a SCI get the energy to accomplish the goal? The desire to accomplish the goals comes from the strength of the vision, dream or picture that the person with a SCI has. Rank (1945) claims that will starts with a dream. The
dream becomes a vision. The vision transcends to will. The will then leads to goals and eventually to action if the dream is strong enough and if the person really wants the dream. Rick Hansen is a perfect example of a person with a SCI whose dream was so strong that he did not allow anything to prevent him from completing his goal, which was a world tour.

One of the problems with being a person with a SCI is that often things don’t work out the way you plan them. Individuals with SCI can have all the information they need, think realistically, be flexible and willing to adapt and change, set reasonable goals, do everything they can; and still fail through no fault of their own. When this happens, the pent-up emotions, or as JC stated, that low-level anger and frustration can explode into a devastating emotional outburst. Unfortunately, these outbursts are sometimes directed at the people who are the closest to them. The source of the frustration is not the event alone but an accumulation of frustrating and angering events that build over a long period of time. This affect is sometimes released like a dam bursting or a volcano erupting. The person may yell and scream using foul language and display violent behaviour, like throwing and breaking things. The triggering event is usually by itself not that large but in the context of that situation at that time acts as the fuse to trigger a tremendous emotional release.

An example of this was given by one of the participants in the research. He was at a party with his girlfriend having a great time when he blew the condom that was attached to his penis that emptied his urine into to his leg-bag. His pants were soaked in urine and the excess dripped onto the floor. His girlfriend was used to it and his friends understood, but he still lost his temper and blew-up and had a big fight with his girlfriend
and was nasty to everyone who tried to help. BA said that he felt bad afterwards but his relationship was never quite the same with his girlfriend after that.

One time, while making macaroni, I reached up and pulled a two-pound box of macaroni off the self. The only problem was that the housekeeper who came twice a week had put the box in backwards and as soon as I pulled it off the shelf the end tipped towards the floor and the entire box of macaroni emptied onto the floor. I had a tremendous temper tantrum that lasted for several minutes. A large part of the frustration is the enormous amounts of time and effort required to correct these seemingly trivial situations. To an able-bodied person it’s not a big deal to change their clothes or clean up some macaroni but to someone in a chair these can be major undertakings.

These tremendous emotional displays are signs that individuals with a SCI are not adjusting well to their injury. Some people with SCI say that these emotional outbursts are healthy for releasing emotional build-up. The literature demonstrates that those people with SCI who control and regulate their emotions score much higher on scales of adjustment for SCI (Buckelew et al., 1990; Craig et al., 1990; Elliott et al., 1987).

When individuals with SCI experience an incident that triggers these emotions, it is important to acknowledge the fact that you are angry and that you feel all that energy but then use that energy constructively. For example, when BA’s condom broke instead of losing control he could have graciously excused himself from the party and gone home. On the way home he could pick up a nice bottle of wine and when he gets home open the wine and invite his girlfriend to join him for a bath. Tell her that the accident was an opportunity to leave the party early allowing them more time alone together and
that the accident was really a good excuse to have a bath. Feel the anger and channel it into a positive experience by being creative and trying to make it fun.

**Personal attributes.** Attributes are characteristics or qualities that individuals have developed as part of their personality or the way they interact with their environment. When individuals experience trauma as severe as a SCI there is a tendency for them to resort to their personal attributes that were most successful for them in their pre-morbid experience. These attributes may work in the short-term but may prove inadequate over time.

Research has indicated that people with SCI who score poorly on adjustment scales have the following personal attributes:

- External locus of control
- Blaming others
- Poor communication skills
- Abdicating personal responsibility
- Remaining the same, stagnation

People with SCI who test low on scales of adjustment tend to have clusters of negative attributes and coping skills that work together to prevent the person from growing and progressing. They desperately attempt to hold on to what they have, remaining the same because it is safe and comfortable. Suddenly, 15 years have gone by and there is no change in their personal world. It is difficult for individuals with SCI, who have been in a survival mode for many years, to risk their life of comfortable mediocrity to take a chance on success and happiness.

Positive attributes also appear to work in clusters. Using the transcripts from the interviews with the participants of this study and a thorough review of the literature on SCI, the following attributes that contributed to long-term adjustment to SCI identified.
Desire. The primary personal attribute in the agency component of Hope is desire or a deep and abiding will to live and succeed. Desire acts as a catalyst for all the other positive attributes that help a person successfully adapt to their SCI. The participants identified desire as the most important single attribute for adjustment to a SCI. They said:

You need imagination, will and desire and you can accomplish more than you or the able-bodied people around you would suspect. (GG)

That’s what you call desire, that process. So you have a dream of who you want to become, right? What you want to become, who you are is who you are. (TB)

Your burning desire keeps you going forward but then you’ve got these hurdles to get over and that is where you rely on your tools, your skills, and your ability to solve problems. (BA)

The participants maintained that if a person did not have the desire, a deep and abiding will to live and succeed, then they would not adjust to their SCI.

Communication skills. One of the reasons low functioning total quadriplegics score high on scores of adjustment may be that very early in their injury, they realise that they are totally dependent on other people for their survival. They cannot move or feel anything below the neck, therefore, they must adapt and learn positive communication skills quickly or their needs will not be taken care of. If they lose their poise and yell and scream at a nurse or a spouse, they simply will have to wait or not receive service. This forces them to develop their communication skill quickly and develop positive relationships because of necessity.

However, individuals with SCI who have the ability to get in and out of bed themselves and perform basic self care tasks often simplify their environment to the point where they are basically self sufficient and independent. Since they are not forced to develop their communication skills, these skills are often not developed. Therefore many
high functioning individuals with SCI, by striving for independence, often isolate themselves and neglect developing relationships and a social support network.

The participants stressed that communication skills were critical for their quality of life and adjustment to their SCI. Individuals with SCI, especially quadriplegics, depend on other people provide for their survival. This forces people with SCI to develop more significant relationships than average people because of necessity, allowing them greater opportunity to practice and develop their communication skills.

These communication skills include being:

- A good listener
- Empathetic
- Non-judgemental and accepting a person at face value
- Gentle with another person's emotions
- Kind
- Fair
- Respectful
- Patient
- Able to explain what one wants in simple terms (Rogers, 1961)

The participants in the current study stated that the people they communicated with mirrored their behaviour back to them. The participants describe an increased awareness of the importance of their communication skills and of being able to know or read what a person they were talking to was thinking. GG claimed that this was achieved by carefully observing body language and being able to pick up minute cues in the eye and facial movements of the person he is talking with. He also claimed that his ability to pick-up on these minute cues was enhanced because he could not move or feel anything below the neck. The lack of physical distractions, he believed, allowed him to totally tune in to the person he was talking to. Other participants talked about knowing exactly what
the other people were going to say or what they were thinking at that particular moment. It was as if they had shifted to a different level of consciousness. The person's use of communication skills is one of the best indicators of adjustment to SCI.

*Locus of control.* People with SCI who are motivated by external rewards such as money, fame, relationships, or praise do not adjust well to SCI. The problem with external rewards is that sometimes through no fault of their own, individuals with SCI fail to accomplish an external goals such as being accepted into graduate school, getting a job, or finding a girlfriend. If individuals with a SCI were dependent on external sources for their feelings of competence and self worth, then rejection by a prospective employer or girlfriend could have a negative effect and create emotional problems for them.

*Taking personal responsibility.* One of the most important and most difficult attributes that contribute to long term adjustment, improved quality of life, and happiness for individuals with a SCI is taking personal responsibility for their recovery. It is difficult to admit to any responsibility to a SCI where, through no fault of their own, individuals were involved in an accident where they received a SCI. It is easy to place the blame on everyone else instead of assuming personal responsibility for ones own reaction to the SCI.

If people with SCI blame themselves for their accident, it sets them up for ongoing negative emotions that revolve around second guessing themselves and playing the would of, should of, could have game. Assuming responsibility for their part in an accident is different from self-blame. It is healthy for individuals with SCI to realistically assume responsibility for their part in the accident. For example, one participant in the current research (JC) was racing in a pro ski race. He fell and broke his neck. When
asked if he was angry with God for allowing him to break his neck he replied, “I think
God was just as surprised as I was when I broke my neck.” JC believes that sometimes
accidents simply happen and it is pointless to blame anyone. He had raced hundreds of
races. He was trying to do the best he could. He can only assume responsibility for
wanting to race and doing the best he could. Blame is an empty vessel that benefits no
one. It is important to have closure on blame by saying, “I made a mistake,” then forgive
oneself, move on, and make the best of the current situation.

For a person with a SCI, taking personal responsibility involves more than taking
responsibility for your own actions in the accident; it involves taking responsibility for
every aspect of existence. The question arises, “How can a person experiencing total
quadriplegia be personally responsible for bedsores?” The answer is through their
communication skills. LN who is a C-5 complete quadriplegic said, “I suddenly realised
that the world didn’t owe me a living and that no one was going to look after me, so I
have to look after myself.” This person needs someone to get them out of bed each
morning and help them get dressed. He also needs someone to help prepare his meals.
The point is that each person’s independence is relative; therefore, if a person cannot
perform a task and someone else must do it for them, then it is still the responsibility of
the person with a SCI to make certain that the task is performed correctly. Individuals
with a SCI must take responsibility for every aspect of their existence including:

- Money to support self and family
- Support services
- Personal health and self-care
- Diet and nutrition
- Education
- Transportation
- Employment
- Relationships
In reality, this means that although individuals with a SCI may not be able to cook their own meals, they must take charge and prepare their own menus. They must make certain that they are receiving enough vitamins and mineral supplements and enough pure water. It is the individuals with SCI who are responsible for checking their skin each day and making certain that their catheterisation and bowel routines are on time. It is their responsibility to ensure that all the tasks of daily living are done properly and on time. Good health for people with SCI requires that they train their bodies by adhering to a rigid schedule of eating at set times, drinking fluids every two hours, catheterising at set intervals, having their bowel routines at fixed intervals, stretching, working out at fixed times, working regular hours, taking medications at fixed times, and sleeping at the same time each night.

LN is convinced that the body will adapt to almost any pattern. He had a lot of spasms and was taking anti-spasm medication. He found that his body had adapted to the prescription drugs for spasticity. By using a strict regime of good food, vitamins, stretching, exercise, without using alcohol, caffeine, or street drugs, and a strict adherence to a schedule for his personal care LN was able to use less and less medication until, at the time of his interview, basically he was drug free.

It is important to remember that many decisions that a person with a SCI makes early in rehabilitation are lifetime decisions. For example a decision to stretch or not stretch for a half-hour a day makes a big impact 15 years later. Flexibility is probably the most difficult thing to maintain over the life course of a SCI. Without daily exercise and stretching, the body gradually goes into contractures and the joints start aching after five
or six years. Individuals with a SCI must also take personal responsibility for their emotions and how they react to stressful situations. No event or person makes one do anything. Individuals choose to react with anger or with calmness to any situation. People with a SCI must take responsibility for their physical, emotional, and spiritual well being without using the accident as an excuse for inappropriate behaviour.

**Realistic thinking.** Realistic thinking involves knowing the difference between pain and injury. It involves understanding one’s limitations. It involves wisdom. It involves understanding one’s new body. It is important for individuals with SCI to attempt some new things and expand their horizons to take some risks but it is important to realise the consequences of those acts. For example, when training and competing in a wheelchair sport like basketball or marathons, there is a tendency for the young SCI male to train too hard. BA completed a marathon six months after he broke his back. Fifteen years later, he can’t race any more because of permanent damage to his left arm. ES wheels in international marathons and now has chronic pain in his neck because of looking up from a bent over position while wheeling. CS walked exclusively for six years with forearm crutches and after 13 years had three hernia operations. JC stated that if he could give advice to fresh breaks, it would be to temper their enthusiasm because joints are not an unrestricted and unlimited mechanical device and we only have one body. The hands, wrists, shoulders, elbows, and neck take a tremendous amount of strain in wheeling a wheelchair or walking on crutches. It is important to stretch them out twice a day along with the back and legs. Moderation is the key focusing on a slow steady progression involving all the muscle groups so they can support each other.
An ongoing problem, especially in quadriplegia, is that usually the muscular return is not symmetrical, the antagonistic muscles do not support each other and, with exercise, the discrepancy between these antagonistic muscles increases, resulting in an abnormal twisting of the joints. The constant use of these joints with muscular imbalance invariably results in arthritis. With modern medicine, it is possible to spend 50 or 60 years in a wheelchair. If individuals with SCI overextend themselves too much in the initial five years, they will suffer problems with their joints later in their disability.

Realistic thinking involves understanding that one has a SCI, that one is not able-bodied, and that one’s joints are not an unlimited mechanical device. It also involves dressing warmer in the wintertime, especially the feet and legs because you cannot feel them. It means making certain to catheterise on time, preventing dysreflexia. In the summertime, it means drinking lots of water, wearing sunscreen, a hat, and staying in the shade. It means not trying to do something new without a spotter to prevent a serious injury. It require a person to use wisdom and good judgement to know when to struggle and do something by one’s self and when to ask for help. Realistic thinking is understanding the long-term consequences of one’s actions and determining if the short-term rewards are worth the risk.

Creativity and imagination. All the participants in the study were tremendous problem solvers. GG stated that there was usually a way around any obstacle or a solution to any problem. For example, instead of using a skill saw free hand, GG mounted it under a table so that the blade was above the plane of the table. This allowed him to cut wooden items without risking dropping the saw. CS could only use his left hand a little and he learned that if he held his camera upside down, he could control the shutter with his left
thumb from under the camera and steady the camera with his right hand. The participants each hold their pen differently to write. GG states that necessity is the mother of invention. If people with SCI want to do something badly enough or need to do something, they will usually figure out a way of accomplishing the task or if they can’t do it then, they will ask for help.

*Perseverance and determination.* Perseverance and determination are linked with creativity and imagination. If one tries long enough and hard enough, usually there is a solution to most problems. Each person with a SCI is injured in a slightly different way. CS realised that in order for him to be safe when he was out alone in his chair, he needed to be able to transfer from the ground up into his chair. It took CS three months of practising one hour or more each day before he perfected his transfer technique. CS had to figure out how he could perform this task with the return he had. It required creativity, perseverance and determination to fight off discouragement and finally achieve the goal.

JC is a partial lesion quadriplegic. First they put him on a stand-up board. Then he walked on parallel bars in the water. Then parallel bars on land. Next he walked on forearm crutches. At first, he fell on every step and the nurses caught him. This took courage and the ability to trust the spotters. Slowly, over a period of approximately three months, he could walk alone with just his crutches. This required courage to push the envelope and tremendous determination not to give up.

In order to progress, it is essential that the person with a SCI pushes the envelope just a little and is creative. Too often people with SCI give up when the finish line is almost within reach. With science and technology making such rapid advances in spinal cord research, it is important for each individual with a SCI to maintain as much strength
and flexibility as possible. It takes a very long time for nerves to heal and it take
tremendous determination for a person with a SCI to continue to work hard when there
are no improvements over a period of years. But, it is necessary for a person with a SCI
to continue to stretch and workout daily otherwise they will lose strength and flexibility
and lose their abilities that they currently enjoy.

**Risk taking.** The consensus of the participants was that it is important to have
courage but unnecessary risks should be avoided. They stated that they weighed things
out more now than before their accident because, if they get hurt or sick and end up in
bed or in the hospital, they might never get back to the level of function they now enjoy.
LN said:

> My health is more important than anything else. I want to maintain my health as
> much as possible and if I am going to do something to harm myself, I want to
> eliminate as much risk as possible. Like sky diving, I am not going to sky dive
> without a buddy because I know I can’t. (LN)

The secret is to minimise the risks and eliminate unnecessary risks but still do the
activity using creative adaptations and appropriate accommodations. For example, water
skiing, snow skiing, sailing, gliding, driving a car, scuba diving, and parachuting are
activities involving a high-risk for individuals with SCI. However, with proper
equipment, training and adaptations, people with SCI can participate in most activities
with acceptable risk levels.

**Love of self.** Many people with SCI look at themselves as incomplete or less than
they were before their accident. They buy into the social construction of disability and
allow themselves to be stigmatised as a second class citizen. If people measure
themselves as a human being based solely in terms of how much money they earn, how
much work they can do, or how well they can perform sexually, they are setting
themselves up for disappointment. To not feel inferior or incomplete, one must use a standard of measurement based on something besides the physical realm. The standard of measurement should be spiritual in nature, based on something greater than themselves. GG was the only person in the group who did not believe in God. He believed that he was only one small part of the universe. He believed that life and death and sickness and health were all the same. He had been hurt and crippled but this was his adventure, his journey and the path he was to take for enlightenment. He has embraced this journey and feels that he is a whole person who exists in a wheelchair and has to do things a little bit differently. He enjoys his life and sees his role as a mentor to younger breaks. LN summarises the feeling of the other participants very succinctly when he said, “God loves me the way I am. Therefore I can love me the way I am.” The other participants are all of different religious affiliations; however, each of them love themselves and use their own standard to judge themselves on their accomplishments. They are realistic about what their abilities are and what is reasonable for them to accomplish.

Relationships. Men who experience SCI are no different than other men. They desire meaningful relationships and a healthy sex life (Crewe, 1987; Elliott et al., 1992; Fine & Asch, 1988). The participants thought that their sex lives were over when they experienced a SCI and thought that they would never have another meaningful relationship or experience intimacy with a woman again. They felt that nobody would want them because they looked on themselves as less than before or incomplete because they could not perform sexually, and that their partner would have to do everything for them. This is consistent with the literature on SCI (Derogitis, 1980; Farrow, 1990; Romeo 1993; Singh & Magner, 1975; Teal & Athelstan, 1975)
Only one of the six participants in this research maintained the relationship he was involved in past the rehabilitation stage. All five of the other participants expressed a sincere desire to be involved in a meaningful relationship but had remained living alone. Each of them had been in a meaningful relationship but none of the relationships had survived longer than two years. They had all been SCI a minimum of 11 years at the time of the interviews. When I asked each of them why they thought they were still alone the general consensus was that in their relationships it appeared that everything went well until it came time to cohabit. Then things slowly deteriorated as the reality of living together and living full time with a person with a serious impairment sank in. It seemed that, for the participants, living with an able-bodied person made them feel disabled. BA summed it up best when he said:

I would rather live alone and be moderately happy than live with someone and feel incompetent. (BA)

Relationships for people with SCI, based on worth, are predictive of less social and physical impairment over time (Elliott et al., 1992). Herrick et al. (1994) found that the type of social support was predictive of health complications and that health complications were predictive of poor adjustment and depression. Relationships based on need when someone depended on someone else were predictive of health complications.

JC, the only participant who remained in a relationship, credited the success of his marriage to the fact that they:

- shared responsibilities
- maintained outside friends and interests
- he continued his education and she continued her job
- he graduated and obtained a good job
- they had a good sex life and had two children.
The only participant who is currently experiencing health problems is LN who has a C-5 complete lesion quadriplegic and has been injured for 23 years. This is consistent with the research of Herrick et al. (1994) that points out that the level of the break and the time since injury where two of the greatest predictors of individuals with SCI experiencing health problems.

With the exception of JC, the participants remain living alone, avoiding the dependency and negative affectivity that can be generated when person with a SCI lives in an environment where an able-bodied person could demonstrate how incompetent they were. As BA pointed out, the divorce rate for the general population is about fifty percent and when you add something as serious as SCI to the mix it's not surprising so many men with SCI end up living alone.

Barriers. When people with SCI are first injured, they are given a tremendous amount of attention. They have daily physiotherapy, occupational therapy, recreational therapy, twenty-four hour a day care, daily visits by friends. For a long time they feel stronger each day and feel as if they are progressing. Then they are released from the hospital. It's exciting, challenging, and there is a new environment to conquer. Many go back to school while others retrain and go to work. The body is still getting stronger and they are still optimistic that they can have it all: a good relationship, a good job, and a future.

It appears that about five years after the accident the body is no longer improving. The joints in the arms, neck, and back start aching a little. Those who graduate from university find out the harsh reality that there are few jobs for anyone, including a person with a SCI. The original equipment, given to a person with a SCI in the hospital, begins
to seriously deteriorate. Usually their income is fixed but the cost of food, equipment, housing, transportation, and education increase yearly. Government and insurance companies find ways to make people with SCI pay more for current services and charge for services that were once free. It takes longer to get anywhere by handi-bus and it’s inconvenient to use a vehicle in winter. Many places still don’t have elevators or automatic doors. Even one stair can be an insurmountable barrier to a person in an electric chair. When someone has to help you up stairs, get through some doors, or get into the restroom it makes you feel disabled. People are always asking you to tell your story and asking you weird questions. Many people look at you with pity in their eyes and are condescending in their behaviour towards you. You can never simply do something spontaneously because you have to plan for catheterisation, bowel routines, diet, and travel arrangements. All these factors act in concert to helping to stigmatise individuals with SCI and make them feel inferior, diminished — disabled.

The participants in this research identified money and time as the most difficult barriers they had to deal with on an ongoing basis. If they had enough money they felt that they could control their environment, remove physical barriers, hire sufficient help and provide themselves with transportation, and purchase necessary equipment. Having financial security would solve many of the problems with time and spontaneity because they could afford to hire someone to assist them. Brown et al. (1987) and Trieschmann (1988) identified financial security as the most important factor in adjustment to disability. Brown et al. (1987) further added that when men with a disability had resources, they allocated their time similarly to the normal able-bodied population.
It isn’t any one barrier or obstacle that tends to block a person from achieving success. It’s constantly dealing with a never-ending array of medical complications, physical barriers, and the psychosocial stigma of society. This includes: never having enough time, struggling to get enough money; constantly repairing equipment; and constantly having to deal with red tape with insurance companies and government agencies day after day week after week and month after month. There are no days off from a SCI. Many people get exhausted from the constant stress of the tremendous physical and mental grind.

An important barrier to long-term adjustment to SCI is the disinsentives created by government programs and insurance companies that tend to penalise individuals with SCI. If they struggle and becomes stronger and more competent, then they are deemed employable and must go off benefits and get a job because now they are fit enough to work. Once they are employed they become ineligible to receive the benefits they were receiving they started working. People with SCI are more susceptible to periods of hospitalisation due to illness and when they are away from work for more than a few weeks, they are often fired. People with SCI are many times hired on programs that are subsidised by the Government. When these programs end or if a firm downsizes these employees are the first to go. Individuals with a SCI are caught in a catch-22 position because if they work over a certain length of time and then they are fired, they are not eligible to receive the benefits they were receiving before they started working. Unable to return to their disability insurance and unable to work, they must now apply for welfare, which is not only stigmatising but provides less money than they were receiving before they started working. There is no guarantee they will be able to get back on any
government program and they are not eligible for disability on private insurance policies because now they are deemed employable. The definition of disability used by the government and by insurance companies is someone who cannot be employed. It is easier for many people with SCI to stay in their current situation that is safe than to risk that security for an unsure and risky future by trying to change. It takes tremendous courage and self-confidence to take that risk and give up a secure mediocre existence and actually become employed.

Life situations. People with a SCI have to deal with all the problems that every one else has. However, SCI acts as a major stressor, which may be just enough to push a individuals past their ability to copc. Stress is cumulative (Selye, 1976). Individuals with a SCI already have considerable stress in their life without adding serious stressors such as the death of a loved one, hospitalisation or the loss of a relationship. The added stress of a significant life event may be enough to push them past their ability to cope Selye, (1976). Individuals can be surviving, coping quite well, when another major life event such as the death of a loved one triggers a response that unlocks emotions or affect that have been stored, “Frozen in time” from the original trauma of a SCI. (Damasio, 1994; Hohmann, 1966).

Defrosting Unfinished Business

The process of “Defrosting Unfinished Business” is at the hub of long-term adjustment to SCI and it is the pivotal point around which the healing process for trauma occurs. Previously, in the discussion of World Collapse I outlined the process of the “Buffering effect” (Damasio 1994;Horowitz,1986) and “denial” (Caplan, 1987), that stored affect in the sub-conscious that was unavailable to cognition, “Frozen in time.”
The affect was stored because the trauma and stress experienced at the time of the accident exceeded the person’s tolerance and ability to cope. This affect remains unavailable to cognition through a process of avoidance until the person is cognitively ready to process these emotions. When the person is cognitively ready to “Defrost” the “Frozen” affect, an intrusive event will act as a trigger releasing repressed emotions (Horowitz, 1986). When this happens a person experiences a disequilibrium because the newly released affect places an increased strain on the person’s tolerance or capacity level to accommodate the additional affect that had been “Frozen in time” (Horowitz, 1986).

There is a danger that once the affect is released the person will not be able to cope with the added emotional affect. This new emotional release may push a person beyond his capacity to cope and adjust and he may regress and experience another “World Collapse” and enter into the “Treadmill to Despair.” The person will continue to experience the affect and disequilibrium until he is able to increase his capacity and tolerance to deal with this new source of stress and emotional release.

To accomplish this, it is necessary for him to embrace hope. Hope is a combination of desire and pathways for successfully dealing with these negative events and emotions that are a cognitive reality (Elliott et al., 1991). In order for the person to rebalance, he must take action and expand his tolerance to this new affect and stress by increasing his coping skills, adopting new and more appropriate coping skills, or changing his environment. This increased tolerance and capacity allows him the ability to desensitise and absorb the affect. In the process of re-balancing, he experiences growth (Green, 1984) and an expansion of consciousness (Neuman, 1985; Wilber, 1988). This
allows him to transcend his previous definition of self and reconstruct a new definition of self. This process continues in a cyclical fashion until the issues responsible for the affect that was “Frozen in time” are “Defrosted,” desensitised, and absorbed.

This process occurs naturally as the person matures, develops appropriate coping skills, and becomes cognitively able to deal with issues that have been “Frozen in time.” However, some issues are so huge or people have been so damaged emotionally that they become stuck and are unable to process these issues that have been “Frozen in time.” In these instances, for them to heal and progress, it is necessary for them to get help in the form of counselling.

Summary

Understanding the trauma of SCI has been presented in four parts. First the experience of “World collapse” and the necessary descent was discussed, followed by “Long-term adjustment,” which was discussed in three parts namely: Survival; Treadmill to Despair; and Hope: The Healing Path. The parts were discussed separately and shown as Figures 1, 2, 3, and 4 to better explain and introduce the major components of the complete model for “Understanding the Trauma of SCI.” This complete model is presented as Figure 5 and is a combination of the other four models that have simply been superimposed one on top of the other. The four major parts of the model for “Understanding the Trauma of SCI,” presented as Figure 5, do not act discretely or in a linear fashion but as an integrated, dynamic, cyclical process where different operations can be occurring simultaneously.

The starting point of the model represented in Figure 5 is the actual “Lived experience” surrounding the accident. This includes the organic biological,
environmental, and psychosocial issues that they are confronted with during their accident and the subsequent rehabilitation process.

At the very heart of this theoretical approach to “Understanding the Trauma of SCI” is the importance of the pre-morbid personality. People with SCI are not a homogeneous group and enter into the experience of SCI with different coping skills, attributes, and personal resources. The pre-morbid personality, of people who experience a SCI, acts as a filter through which they attach meaning and significance to their losses, ultimately affecting how they react to their SCI.

It is theorised that before individuals can make an adjustment or an accommodation to their SCI that first they must experience “World Collapse,” which consolidates and crystallises their pre-existing coping mechanisms. Individuals, who are overwhelmed from the trauma of SCI, automatically alter their ANS, creating a “Buffering effect” that postpones the experiencing of intense emotions by storing affect in the sub-conscious. Individuals experiencing SCI also use denial to cognitively re-frame data, protecting themselves from experiencing excessive affect and the intense emotions surrounding the trauma of SCI. The affect, stored and deferred by the “Buffering effect” and denial effectively becomes “Frozen in time” unavailable to cognition.

“World Collapse” usually occurs at some point in intensive care or in the rehabilitation setting creating feelings of fragmentation, dissociation, and low self-esteem forcing individuals with a SCI injury to resort to pre-morbid coping skills and shift into a survival mode, where they usually remain until after release from rehabilitation. Once they are released into the community they are faced with a new and hostile environment, requiring them to renegotiate every aspect of their existence outside of the safety net of
the rehabilitation setting. They are faced with the decision of continuing to survive, to give up and commit suicide or escape into Fantasyland and the Treadmill to despair, or to embrace Hope: The healing path.

It is theorised that people with a SCI will continue on a pathway until they experience a barrier or life situation, triggering the release of affect that had been stored by the “Buffering effect” or which forces them out of denial, causing them to cognitively re-frame their situation. Individuals with SCI who have experienced a triggering event, causing them disequilibrium, must now process the freshly released affect that had been “Frozen in Time,” unavailable to consciousness, using a process labelled as “Defrosting Unfinished Business.” This process, outlined in Figure 6, occurs gradually over time and if successfully negotiated by individuals, results in them being able to desensitise and absorb the affect, cognitively restructure their definition of themselves, and increase their tolerance to stress. However, if the individuals possess inadequate coping skills, attributes, and resources to deal with the released affect then they may be forced to escape to the Treadmill to despair or Survival until the are cognitively ready to process and deal with the issues that have been released. People with SCI can cycle in and out of any of the three pathways depending on their pre-morbid personalities and the resources they can muster to deal with the additional barriers and life situations that emerge during the life course of a SCI. The process of “Defrosting Unfinished Business” is pivotal for long-term adjustment to SCI and is described and discussed in more detail in the Implications for Counselling section.
Implications for Counselling

The only thing stopping a person with a SCI from accomplishing their goals is desire, imagination, equipment and perseverance.

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Brown (1992) defined the role of a counsellor as enabling the individual with a disability to function as effectively as possible in the domains that he or she personally sees as critical to a competent life style. Trieschmann (1988) believed the role of the counsellor is to help the client or consumer function as efficiently as possible in his or her own environment. The general consensus in rehabilitation literature is that the counsellor’s role is to maximise the potential of individuals with a SCI and empower them to the point where they will make appropriate decisions on their own and become as independent as possible. The question is, “How can the counsellor facilitate that process?”

For rehabilitation counsellors, this means they should first examine their own feelings and perceptions about disability. Then they should examine the issues of:

- Their own feelings about loss
- Guilt about being healthy and whole while their client is impaired or disabled
- Their feelings about sexuality and disability
- Their own issues
- Absence of neurotic patterns that would interfere with communications (Yalom, 1986)

In rehabilitation counselling it is important to be eclectic. The secret is to be able to do a valid assessment, pick the appropriate psychological theory, know what that theory will and will not do for your client, and be able to execute the proper course of therapy. Thomas and Parker (1992) pointed out that it is critical to have a sound theoretical background in a particular theoretical approach before attempting to use it to
counsel a client. Caution must be exercised because clients may experience psychological
damage if the counsellor uses a theoretical approach that they are not familiar with or do
not understand (Thomas & Parker, 1992). It is important for counsellors to be aware of
their limitations and that they refer the client to the proper counsellor if they cannot
appropriately deal with a client's specific needs.

Bracken et al. (1981) observed that the critical time for counselling and
intervention was in the rehabilitation stage of a SCI. Yet little time is spent in the
rehabilitation setting dealing with psychological or social rehabilitation (Trieschmann,
1988). Bracken et al. (1981) suggests that, at the time of discharge, many people with
SCI have serious problems with anger, anxiety, and depression. It has been demonstrated
that pre-morbid personality is highly predictive of adjustment to SCI (Bracken et al.,
1981; Jubala & Brenes, 1988; McCann & Pearlman, 1990; Young et al., 1982). The
experiences of the participants of this research are consistent with the literature on SCI
and are demonstrated by BA.

The professionals have no idea of what is going on. They know the physiological
aspects and OK the bones healed, the tissues healed, and the scars healed and blah,
blah ,blah, but they don't deal with the psychological aspects and nobody really did.
So they just throw you in with a bunch of other gimps and hopefully you will sort it
out for yourselves. (BA)

Most of the psychological counselling occurred in groups, however the participants didn't
think that the professionals really understood what they were experiencing. JC also made
the point that, “I think that counselling is so complex that they have to somehow pick up
on who they are dealing with.” During the rehabilitation process little time or energy was
spent on identifying who the person with the SCI was, what coping skills, personal
attributes and personal resources the person had before his accident. Linehan (1993)
made the observation that it is important that an assessment be made as early as possible after an accident to determine the pre-morbid personality of a person with a SCI to help determine appropriate interventions.

The participants found that the modelling effect of other people with SCI was one of the most important factors for motivating them and helping them maintain hope.

Seeing more successful people in chairs, that would be the thing. Just like seeing you is an inspiration to me because you are working on a Ph.D. and I am just working at a BA type thing. So there is something more out there and just one example isn't good enough. Because you can train, even conditioning type thing, this guy is successful keep bringing this guy in all the time. That isn't good enough. You want a variety to see. Some of them you are going to relate to and you can sit down and talk to and they will inspire you automatically. (TB)

My major complaint about an able-bodied counsellor with a disabled person in a chair is even though they are saying the right things to you and you know it, they're talking out of a book. (TB)

It would appear on the basis of the literature and on the observations made by the participants in this research that the counselling process should begin as soon as possible in the rehabilitation setting. A complete assessment and inventory of the person's pre-morbid personality should be undertaken (Linehan, 1993). If possible it is recommended by the participants that the counsellor be spinal cord injured and a series of other people with spinal cord injuries should be used in the first few weeks to help in modelling and motivation.

It is advantageous to start the assessment process by using a humanistic approach that emphasises congruence, unconditional positive regard, and empathy (Rogers 1961). This creates a non-judgemental environment of trust, unconditional positive regard and empathy, which contribute to a positive relationship, which is the starting point of the counselling process (Brown, 1992; Corsini, 1989; Rogers, 1961; Thomas & Parker, 1992;
Vargo, 1992; Yalom, 1980). However, it is critical that one’s approach to counselling be congruent and consistent with one’s belief system and philosophy of life.

Rogers (1961) maintained that the relationship itself will create an atmosphere wherein the clients will self-activate and heal themselves. The relationship and the process of engagement and trying to find a solution to a problem may be enough to eliminate it. When clients are engaged in trying to find a solution to a problem, they look away from the problem and often the problem vanishes (Yalom, 1980).

Once a relationship has been established, the question arises, “What issues need to be addressed?” When (LN) was summarising what he thought a counsellor should do for a person with a SCI he said:

The big question often is, “How am I going to take care of my family?” “What am I going to do to live on or eat or where are my dollars going to come from in order to cover the cost of food and equipment?” The first thing you have to do is alleviate some of those concerns. Reduce the tension by:

- Working through the disability phase and becoming healthy and stabilize the injury.
- Now accommodations
- How am I going to get the support services I need?
- Transportation- to and from work or school.
- Most people only look at one piece of the puzzle and when you are working with a person you need to look at the whole person.
- How is this person going to live the rest of his or her life and maintain as independent a life style as possible, become as self sufficient as possible and have as fulfilling a life as possible.
- It’s only by having every piece of the puzzle in place from finances to recreation.
- Problems are equipment and finances. The cost of chairs are 4-6 grand. Money is a key issue.

(LN)

Clients should have a choice as to what they are doing in the counselling sessions (Brown, 1992; Lenny, 1993; Rogers, 1961; Swain, Finkelstein, French, & Oliver, 1993; Yalom, 1980). This allows clients to explore any issue that may be bothering them.
Clients' concerns may appear trivial or serious in the view of the counsellor. The rehabilitation counsellor must remember that the presenting problem or concern is often not the real issue but merely a symptom of a deeper concern. The counsellor should allow sufficient time in discussion to ensure the client has an opportunity to open up deeper concerns. If the client opens up an issue, which is diametrically opposed to the values of the counsellor or is dangerous to the client, the counsellor may be able to use this moment as an opening to a valuable counselling opportunity. Allowing clients the opportunity to have choice in the direction of the counselling is a starting point for them accepting responsibility for their behaviour and their own care.

Hornby (1992) concluded that disability has a serious impact on the entire family. In fact, Harris, Patel, Greer, and Naughton (1973) stated that the family determines the reaction of the patient to his disability. When a member of a family acquires a SCI it throws the entire family into disequilibrium. Part of the problem is that each member of the family is affected differently and each member heals at a different rate. The patient may be OK with his situation but it may take some of the other members of the family, for example, the father or mother, longer to adjust to the SCI than the patient. Therefore it is important that the counsellor familiarises themselves with family systems theories like the Transactional, Ecological, and Family Systems approaches. When family members are out of synchronisation with the recovery of the person with a SCI, it is called triangulation and can cause dissonance and problems in the recovery process.

It is important that the confidentiality of the client be respected and maintained even with the family (Brown, 1992). Care should be taken to get permission for the counsellor to talk to the family in private because there may be issues of imminent
divorce in the case of a spouse or issues of inheritance if the client is near death. The
counsellor should interview the family in the presence of the client and spend time in the
home in order to get a true picture of the relationship between the client and the family.

Loss of employment can mean the loss of finances and poverty, loss of prestige
and status, and a shift in the roles of the family (Holosko, 1992). However, some people
with SCI may not want or need work immediately (Brown, 1992). If the client desires
employment the counsellor should be prepared to provide support by building on the
client’s strengths, helping the client understand that unemployment is high, fostering job
seeking behaviours, and helping the client set and achieve goals (Holosko, 1992).

The counsellor should help the client engage in leisure activities. These activities
should involve more than simply observing an event. Brown (1992) states that it appears
that people with disabilities who have a higher and broader based leisure style find their
way back to employment much more rapidly. Leisure activities such as sports and
recreation build strength, endurance, flexibility, and also contribute to self-esteem and
motivation.

The counsellor should also perform an ecological evaluation of the client’s
environment act as an advocate to help him maximise its functional efficiency. This
would include anything, like building a ramp that would make his home environment
more efficient and user friendly.

Sexuality is an issue that is mentioned only in passing in most of the literature on
stress that dealing with the issue of sexuality is critical in the recovery of people with
SCI. Men with impairment that limits or eliminates their ability to obtain an erection or
perform an ejaculation may have serious problems with self-worth and feelings of inadequacy. In fact Hablin (1968) made the point that, until the issues of sexuality are addressed in SCI men, counselling in other areas will be of little benefit to a person with a SCI in terms of adjustment. There are new drugs which are available that can allow men with SCI to achieve erections and ejaculation. However, these drugs should only be prescribed by a knowledgeable doctor and used with caution and with the aid of the doctor who prescribes the drugs. The misuse of these drugs can cause serious damage to the blood vessels in the penis and lead to permanent impotence, so care must be exercised when using these medications. The early use of these drugs may also inhibit the return of normal sexual function to a person with SCI.

Yalom (1980) stated that the counsellor should be careful not to do anything, which will be destructive to the client. He or she should be receptive and understand the deeper meaning of what is occurring in the session. The counsellor should employ good timing and pace because knowing when to use an intervention is as important as knowing how. However, the success of psychological interventions in enhancing long-term adjustment to SCI has not been fully established (Craig et al., 1990).

In a study by Brown (1992), people with disabilities identified the following attributes, besides the ones already mentioned, that rehabilitation counsellors should possess. These are:

- The counsellor should have a sense of humour;
- The counsellor should be skilled in reading body language;
- That counsellors provide services for a sufficient length of time to make certain the client does not regress because SCI is ongoing and never ending, and with additional stress, a client can regress;
- The counsellor should follow up on clients;
• The counsellor should have a good voice. How a counsellor presents information is as important as what he or she says. Often tone says more than words.

The Importance Of “Defrosting Unfinished Business”

A better understanding of the key concepts of “Frozen in time” caused by the “Buffering effect” and denial and the concept of “Defrosting Unfinished Business” are important and should be considered in the counselling for long-term adjustment to SCI. Often these concepts are not included in the counselling procedures for individuals with SCI. Instead of encouraging a process of talking more about the accident and how they feel and processing those issues individuals with SCI are encouraged to let go of the past, don’t cry over spilt milk, move on, focus on the here and now, and accept their chair. The focus is on the basic essentials of survival like: getting stronger and more functional, getting a place to live, getting enough money to support yourself and your family, getting transportation, getting a job or more education. Once those basic needs have been taken care of individuals with SCI are often left to their own resources. This type of approach encourages people with SCI to bury their emotions and adopt a survivalist mentality and fill up the day with so much activity that there is no time to think about processing emotions.

The problem is that because of the “Buffering effect” and denial often huge emotional issues are put aside and stored, “Frozen in time,” unavailable to consciousness (Damasio, 1994; Horowitz, 1986). There are serious consequences if the issues are not dealt with and the affect released. The longer the avoidance of cognitive access to the emotional affect of traumatic issues that have been “Frozen in time,” the greater the suffering and psychological distress the person experiences (Engel, 1964; Wirtz &
There is also strong evidence that if the stored affect and stress from unresolved issues is not released and absorbed that it can lead to serious somatic problems (Glassman, 1998; Kathol, 1985; Michealson & Gold, 1998; Pennebaker, 1989; Wegner, Short, Blake, & Page, 1990).

There is a myth that has been perpetuated, that “Time heals all wounds.” Research has shown this to be false and that stress and depression do not necessarily diminish with time (Craig et al., 1990; Frank, Van Valin, & Elliott, 1987). Research has also shown that problems of anger, anxiety, and depression are not being addressed in rehabilitation (Bracken et al., 1981; Craig et al., 1990). The danger of not addressing these problems, such as depression, early in the rehabilitation process is that if they are not addressed they may become internalised as an enduring negative cognitive schemata (Briere, 1996). Once these thought patterns are ingrained they are more difficult to change. Therefore, it is important to address these issues as early as possible and neutralise their long-term impact.

The Counselling Process For “Defrosting Unfinished Business”

When people experience a SCI the trauma may be so intense that the body automatically stores much of the emotional affect in a process already discussed as the “Buffering effect.” This affect is stored but, if not released, can create somatic problems. The issues are huge and the stored affect is of such intensity that individuals attempt to avoid dealing with it. They will remain in this state of emotional respite until some triggering event puts them into disequilibrium, forcing them to experience the now released emotions. This is the beginning of a six step cycle of “Defrosting Unfinished Business,” outlined in Figure
6. This dynamic process continues to cycle until the stored affect is absorbed and desensitised (Rachman, 1993). The six steps of this process follow:

Avoidance

The first step in the cycle of “Defrosting Unfinished Business” is avoidance. The issues and the emotional affect are so huge around trauma that people tend to avoid re-experiencing or processing these issues. The counsellor should be aware that, in most cases, the presenting problem is usually not the major source of emotional disequilibrium. The person who has experienced trauma is often cognitively unaware of unprocessed issues and the repressed emotional affect associated with it because their subconscious is protecting them from emotional pain by the coping strategy of avoidance. The affect will remain “Frozen in Time” until something triggers its release. These unresolved issues are often so huge that the person with a SCI is content to survive and not release the stored affect from these issues (Wertz & Harrell, 1987). Individuals who have experienced trauma will avoid opening up issues that are painful to them. This creates increased pressure and distress (Penebaker, 1989; Wegner et al., 1990). Parker (1995) has recommended that clients should not be forced or pushed through denial or to face reality. Individuals who have experienced trauma will usually stay in this “buffered” state until they are cognitively ready to process the affect.

Intrusion

The trigger to release the emotions and cause the person to address the issue that has been “Frozen in Time” is usually an insurmountable barrier or difficult life situation but may be something quite insignificant. BA described an example of a trigger for emotional release in the research when he blew a condom at a party; and another trigger
was when CS dropped a box of macaroni in his kitchen. The degree of emotions expressed in both cases far exceeded the seriousness of the event indicating that the true source of the anger was something else much deeper.

**Disequilibrium**

When people are in disequilibrium, it is a sign that they are not able to cope or adjust to the trauma of a SCI. Some signs of peoples' inability to cope are exaggerated and inappropriate displays of anger, obsessive-compulsive behaviour, avoidance, and the need to constantly talk about their accident or other losses. When a person with a SCI displays these behaviours it can act as an opportunity for therapeutic intervention.

**Therapeutic Window of Opportunity**

Horowitz (1988) points out that, when these emotions are triggered, there is a narrow window of therapeutic opportunity to bring to cognition an understanding of the source of the emotion before healing can occur. If too much of the emotion is released, the person will only feel emotion and no healing will occur (Horowitz, 1988). Conversely, if there is too much cognition and not enough emotion, there will be no emotional healing.

Harter (1988) maintains that the therapeutic context and atmosphere are more important than focusing on the symptoms. This increases the efficacy of unlocking the affect, the stored thoughts and feelings, the unfinished business that has been “Frozen in time” (Harter, 1988). This allows the therapist an opportunity to cognitively understand the source of the affect and correct inaccurate and immature self-perceptions (Harter, 1988). What is required is that the counsellor helps the patients achieve a balance
between emotional release and a cognitive understanding of the issues involved with that emotional release.

There may be no closure because it may be too devastating and harmful for the clients to reach closure. Slowly the stored affect which has been “Frozen in time” is “Defrosted” bringing to consciousness the emotional pain of unfinished business. A gradual “Defrosting” allows individuals with a SCI time to cognitively renegotiate a new reality in light of their new understanding of issues long repressed as they absorb and desensitise the released affect.

Direct Action

When individuals “Defrost” unfinished business the issues and the release of affect may be so overwhelming that their ability to cope and adjust may be exceeded. At this time it is important that counsellors helps their clients maintain hope. As Elliott et al. (1991) and Snyder (1989) outlined, hope is composed of two parts, namely agency and pathways. If individuals are in therapy, they are already motivated to heal. If they are unmotivated then it is extremely important to understand their pre-morbid personality to establish intervention techniques for motivation. Perhaps the most crucial element in maintaining hope is helping individuals with a SCI establish pathways for adjustment and healing. This can be done by helping them remove or circumvent barriers or by learning and using positive coping skills and attributes like redefining success, cognitive restructuring, and creativity. The coping skills that were most stressed by the participants were setting goals and taking direct action.

You always set your goals but you never set your goals too far that they are impossible to reach so that just set your goals at what you know is obtainable and then set new goals all the time. You start off and try and figure out, ok, if I really try I can do this. And once you get there You say, ok, now I want to go up a notch
and then each time you have a successful thing that happens your confidence goes up and you just try and go beyond that. (TB)

I found that when I let go of my goals it was so easy to stay in bed all day. (TB)

I think setting goals and working towards the goals are important and don't worry about attaining the goal. It doesn't have to be realistic in anyway whatsoever. I think the realism will fall out of the doing. Set the goal and get started on it. (BA)

The important thing was to maintain hope.

If you want to do something bad enough you can usually figure out a way to accomplish it. (GG)

Growth

It is through the struggle to rebalance and regain one's equilibrium that a person with a SCI experiences personal growth (Green, 1984). In order to make a successful accommodation or adjustment to a new barrier or situation, individuals with a SCI must expand their existing coping capabilities and personal resources or learn and adopt new attributes or coping skills. This process of growth through adversity (Green, 1984) forces individuals to cognitively redefine themselves and expands their consciousness (Neuman, 1985; Wilber, 1986).

Harvey (1996) maintains that an important part of the growth process is to attach meaning to the losses. Then, to learn and gain insights about these losses, individuals benefit by imparting to others something positive about their experiences. The growth gained, through attempting to rebalance and attaching meaning to the losses, gives people with a SCI the necessary tools to desensitise and absorb the negative affect. This increases their tolerance and capacity to make accommodations to the new problems and situations evoked by the triggering mechanism that precipitated the "Defrosting" process.
The person continues to recycle through this process of “Defrosting Unfinished Business” until the emotional affect that has been “Frozen in time” is cognitively dealt with through absorption and desensitisation (Rachman, 1993).

**Male Issues**

An important aspect of counselling men with SCI comes through understanding the difficulties able-bodied men have had in defining themselves as men in the later part of the twentieth century (Bly, 1990; Keen, 1991). Men have traditionally defined themselves by proving that they are not feminine, weak, dependent, impotent, passive or failures (Goldberg, 1980; Plante, 1989). When men experience SCI they have, in effect, become what they are attempting to prove they are not. The physical injury has made it impossible for them to prove they are men in the old way because the injury removes physical abilities and the stigmatisation of society reinforces a self-conception of individuals with a SCI being devalued and less than they were (Farrell, 1986; Goldberg, 1976, 1980). When a male with a SCI attempts to reclaim his masculinity by adopting pre-morbid methods of proving maleness he only reinforces his self-concept of being diminished and less than before his accident. This diminished view of self can become crystallised as a permanent cognitive schema (Briere, 1996). It is not just the men with SCI who feel diminished because of traditional methods of proving masculinity. Farrell (1986) and Goldberg (1976, 1980) felt that traditional male patterns are self-destructive and that males need to overcome such things as an over-reliance on doing, an impoverished emotional life, a lack of intimate male friends, and a success at all costs mentality. The experience of a SCI and the descent into “World Collapse” allows men the opportunity to change these patterns. However, they are forced to become reluctant
pilgrims and embark on what Campbell (1949) calls “The Hero’s Journey.” The prospective heroes in mythology, as outlined by Campbell (1949), separate themselves from the common day world and venture forth into a region of supernatural wonders. They encounter many difficult situations and win a decisive victory usually with the help of magic and return home with treasures and knowledge to bestow on the people in their homeland. BA explained his experience of SCI as a “journey,” while GG explained his experience in this way:

At that time my feelings were whatever was done, or whatever one did, it was an adventure and the only way one could lose at this point was not doing anything. It didn’t matter whether you win or lose in an adventure, whether you did something and you would end up getting hurt. The fact that you did something meant that you were progressing. That was my attitude at the time and it probably still is. (GG)

TB commented that, “Adjustment is a lifetime ambition.” The experience of a SCI is a journey that is never over. It is important for men with SCI to release their previous psychosocial stereotypic view of themselves imposed by the dominant culture and reconstruct and embrace a new self-identity. This process can be facilitated in a counselling situation by combining the concepts of “The Hero’s Journey” and “Defrosting Unfinished Business.” Yalom (1980) put it most eloquently when he said, “The counsellors’ ‘raison d’être’ was to be midwife to the patient’s yet unlived life.”

Limitations of the Present Research

The original purpose of this study was to explore what happened to men when they experienced the trauma of a SCI and to develop a grounded theory that would explain this phenomenon. The basic rationale for the study was that before counsellors could develop an intervention for adjustment to SCI, they needed to understand what contributed to the trauma that was experienced by a man with a SCI. The hope was that,
by improving an understanding of this experience, this knowledge would contribute to
counselling practice and research in the field of rehabilitation for people with SCI. A
grounded theory was developed in the form of a model that attempts to explain the
phenomenon of “Understanding the Trauma of SCI.” However, there are some
limitations to this study.

The first limitation of this study was the low number of subjects. The advantage
of only having six subjects was that it was possible to generate texts that were, “oriented,
strong, rich, and deep texts—texts which invite dialogue with those who interact with it”
(Van Manen, 1990, p. 21). Despite the text being thick and rich there is a problem of this
model being generalisable to the population of males with SCI because of the low
number of participants.

The second limitation of this study came from the sampling selection process for
participants. The participants were to have a self-perception as having successfully
adjusted to SCI. Self-rating for adjustment, quality of life and satisfaction have been
found to be the best predictors of later satisfaction and appear more stable over time
(Elliott et al., 1991). Despite this evidence, there is no guarantee that all of the
participants were well adjusted to their SCI.

The third limitation of this study may also paradoxically be one of the strengths of
the study because I am a participant observer in this research. The advantage of this is
that I am an insider (Bollnow, 1974) and that I have lived the experience of a SCI. This
allowed me to develop intense, intimate relationships with each of the participants. I took
several steps to make certain that this study was not simply a projection of my own bias.
As outlined in chapter three, I took the emerging themes back to the participants in the
second and third interviews to make perception checks to insure that I understood how these themes resonated with them. These themes were also identified in the extensive literature on SCI, stress, and depression. However, despite the steps taken to access validity the grave potential weakness of this research is the possibility that the results may simply be a projection of my own idiosyncrasies and bias.

A fourth limitation of this research could revolve around the retrospective nature of the study and if the remembered events are portrayed in an accurate and true fashion. Polkinghorne (1988) addressed this issue by pointing out that when analysing retrospective phenomenological accounts of past events that absolute accuracy and truth were not critical. What he considered critical, regardless of accuracy, was that what the person remembered happening and what they remembered as being truth, real or imagined, determined their behaviour and how the person would react to that event. Therefore, in a retrospective study of this nature, it is more important to understand events as the participants remember them and what those events meant to them rather than what happened in an absolute historically accurate account of the event in question.

The true test of the accuracy, validity, and limitations of this study will only be fully comprehended by the reader of this research becoming fully involved in an ongoing conversation with the data. It is through this personal assessment that readers can determine if the text guided them to their own experience of the phenomenon, actual or potential (Oiler, 1982; Osborne, 1994). The reader must also determine if the research uncovered any knowledge (Benner, 1985) and whether this knowledge has any application in the experience of human life (Van Manen, 1990). Van Manen (1990) stated that a good interpretive account, "is collected by lived experience and recollects lived
experience- is validated by lived experience and validates lived experience (p. 27).

Hopefully this study has fulfilled all of these criteria. Ultimately it is left up to the reader to determine the limitations and the validity of this study by assessing the knowledge and understanding garnered from this research and its applicability in real life.

Problems In SCI Research Design

Romeo (1993) concludes that most studies for people with SCI have limited validity because of the way the studies are conducted. First, the participants in these programs are usually subjected to identical treatment without regard to variables such as level of function, age, marriage status, sexual experience, or education (Craig et al., 1990). Second, most SCI research involves volunteers. These studies are, in most cases, self-selecting and self-reporting (Romeo, 1993). This raises the issue of why did the people who volunteered volunteer? Why didn’t some people with SCI volunteer? Are the subjects who did volunteer representative of the SCI population? Are the results transferable to the general population? Third, if a control group is used, are they matched for such attributes as age, education, determination, or courage (Craig et al., 1990; Romeo, 1993)? Fourth, in studies involving self-report there is always the issue of truthfulness (Romeo, 1993); are the subjects being candid and telling the truth? Fifth, researchers approach the subject of SCI with pre-conceived notions of what it is like to have such an experience. The basic assumptions and prejudices of the researcher are often projected into the questions asked, creating a bias in the results. This creates a situation where many researchers then force the data to fit with their pre-conceived notions and assumptions about SCI (Trieschmann, 1988). Sixth, often the number of subjects is so small in SCI research that it is impossible to reject the null hypothesis of no
difference (Craig et al., 1990). Seventh, results of scores are often averaged leading to a misrepresentation of the results. Group averages may obscure potentially important variances in response. Trieschmann (1988) and Knight (1989) have given evidence that people with SCI are not a homogeneous group. Therefore average test scores are not a valid reflection of the SCI population. Eighth, many studies use different definitions of adjustment to SCI (Albrecht & Higgins, 1977). These definitions are often not clearly specified. Ninth, many studies use different measures of outcomes making correlation with other studies difficult at best (Albrecht & Higgins, 1977). Tenth, staff ratings are often used instead of self-rating (Albrecht & Higgins, 1977). Eleventh, physical and psychological elements are often confounded (Albrecht & Higgins 1977). Twelfth, adjustment is the result of a multitude of individual behaviours interacting over an extended period of time and cannot be assessed by studying one aspect of behaviour cross-sectionally, out of context of the interplay of the psychosocial, organic, and environmental aspects of SCI (Albrecht & Higgins, 1977). Thirteenth, many of the psychological tests used for SCI were developed using able-bodied control groups and were developed for able-bodied populations (Craig et al., 1990). Trieschmann (1988) stated, “There is little evidence in the literature to indicate that the usual and currently used psychological tests measure variables that are most relevant to functional performance in life following SCI” (p. 254). Fourteenth, there are few longitudinal studies about the long-term psychological consequences of SCI (Craig et al., 1990). Fifteenth, Trieschmann (1988) pointed out that “There has been a tendency to look for the maladaptive coping responses but not to identify the adaptive ones (p. 97). Sixteenth, Craig et al. (1990) argues that part of the problem with the research in SCI is that the
results are not interpreted correctly.

Given these problems in research in the area of SCI, it is not surprising that many of the results are conflicting and confusing. In fact, Craig et al. (1990) suggests that the success of psychological intervention in enhancing long-term adjustment to SCI has not been firmly established. Craig et al. (1990) maintains that there are no studies in SCI that compare outcomes of specialised psychological programs to traditional rehabilitation services which are matched longitudinally for such measures as age, sex, education and social class. This means that there are no studies that demonstrate which interventions work on which types of patients to achieve long-term adjustment. Dobkin (1994) states:

Neither the numerous retrospective and prospective uncontrolled studies of SCI rehabilitation nor the very few controlled clinical trials that compared types of programs or particular training techniques have clearly demonstrated the efficacy of specific approaches. (p. 33)

There is little evidence to conflict with the statement that current intervention practices in the rehabilitation setting may have a detrimental effect on long-term adjustment for people with SCI (Craig, et al., 1990). What is needed in SCI research is to identify which intervention techniques, attributes, and coping skills work in which situations to maximise long-term adjustment to SCI. The question arises, “How can this best be accomplished?” Before we can begin to identify intervention programs for adjustment to SCI, we must first understand the trauma experienced by individuals with SCI.

Recommendations For Future SCI Research

This research has emphasised the importance that the pre-morbid personality has in dealing with the concomitants of a SCI. It has been suggested that assessments should be made early in the rehabilitation program to identify the attributes and coping skills
individuals bring to their experience of SCI. Bracken et al. (1981) proposed that interventions be initiated as early in the rehabilitation program as possible. This study also suggests that individuals with a SCI can learn to accommodate and deal with trauma and stress by learning key coping skills, obtaining resources, and then mobilising them to improve their satisfaction, quality of life and accommodation to trauma and stress.

However, as demonstrated in the problems of research design for SCI research, there is little evidence to demonstrate which interventions work on which types of patients to achieve long-term adjustment to SCI (Craig et al., 1990; Dobkin, 1994; Winneman et al., 1994). This means that when it comes to psychological interventions in acute care and rehabilitation, at best, it is a guess as to which intervention will help which individuals achieve long-term adjustment to SCI. Craig et al. (1990) recommended that the first thing that would be required to solve this problem is to isolate the determinants of favourable adjustment to SCI. This could be achieved by doing retroactive long-term longitudinal qualitative research with long-term survivors of SCI. Once the determinants of favourable adjustment have been identified then research can be conducted to test the effectiveness of interventions aimed at reducing psychological morbidity. This research would have to take into account the following factors:

- Control groups must be matched for age, sex, education, and social class.
- Control groups should be of an appropriate sample size to ensure there is enough power to reject the hypothesis of no difference.
- Control groups should be compared both short term and long term.

Craig et al. (1990)

It is also recommended that, because of the complex interaction of all the components to psychological adjustment to SCI, long-term qualitative longitudinal studies of ten and twenty years also be used to establish the determinants of favourable long-term
adjustment to SCI. In conclusion, to help clarify which interventions will work on which people for a favourable long-term adjustment to SCI, I recommend that the following research topics be addressed. They are:

- Investigate which programs and interventions correlate with long-term adjustment.
- Establish the optimal length of stay in a rehabilitation setting.
- Investigate the implications of the use of half-way houses after rehabilitation.
- Identify the incidence of suicide and unnecessary deaths in the SCI population.
- Determine prevalence of drug abuse in the SCI population.
- Create a common database for all the provinces in Canada to obtain accurate statistics for the SCI population for information on concerns such as suicides and preventable deaths.
REFERENCES


APPENDIX A
ADVERTISEMENT FOR RESEARCH PARTICIPANTS

WANTED
Spinal Cord Injured Males to Participate in PhD. Dissertation Research Project

PROJECT
Is entitled "The Quest for Wholeness of the Spinal Cord Injured Male"

CONDUCTED BY
Clark Sloan of The University of Calgary under the supervision of Dr. S. Robertson of the Department of Educational Psychology of The University of Calgary

PURPOSE
To determine if the trauma of Spinal Cord Injury has an affect on consciousness or what part consciousness has on a person’s sense of wholeness or adjustment to Spinal Cord Injury.

METHOD
In-depth interviews will be conducted wherein participants will be asked to tell their life history. These interviews will be taped and transcripts will be made. Additional interviews will be needed to verify meaning and go into more depth.

TIME REQUIREMENT
Three to six hours

CRITERIA FOR PARTICIPANTS
- Ten male participants with five being quadriplegic and five being paraplegic
- Minimum five years post-injury
- Verbally fluent with an ability to communicate thoughts, feelings, and perceptions.
- Willing to be involved in the study.
- Have a self-perception of successful adjustment to Spinal Cord Injury.

IF YOU FIT THE CRITERIA FOR THE STUDY AND ARE WILLING TO PARTICIPATE, CONTACT:
Clark Sloan
#407, 647 – 1st Ave. N.E.
Calgary, Alberta T2E 0B5
Or Phone: 263-3445

Once I am contacted by a prospective participant, I will arrange an interview. The first ten participants who meet the criteria will comprise the study group. All prospective participants will be informed as to their status as a participant or as a backup in case someone drops out of the study.

CLARK R. SLOAN
CONSENT FOR RESEARCH PARTICIPATION

I hereby consent to participate as a subject in the research project entitled “The Quest for Wholeness of the Spinal Cord Injured Male: Understanding the Second Life Course” conducted by Clark Sloan under the supervision of Dr. Sharon E. Robertson of the Department of Educational Psychology at The University of Calgary. The purpose of the study is to determine if the trauma of a spinal cord injury has an effect on consciousness and what part consciousness has on the person’s sense of wholeness or adjustment to spinal cord injury. Specifically, the study asks me to: 1) Participate in an in-depth interview in which I will tell my life history; 2) Participate in a series of additional interviews (varying in length and number) in which I will collaborate with the researcher as a co-researcher to verify the meaning of my experiences.

I understand the interviews will be: 1) Semi-structured, informal, open-ended; 2) Tape recorded for later transcription; 3) Conducted at a time and place convenient for me.

I understand that my participation is completely voluntary, and I am free to withdraw from the study at any time I choose, without penalty.

I understand that the results of this research may be published or reported to government agencies, funding agencies, or scientific groups, but my name will not be associated in any way with any published results.

I understand that the results of this project will be coded in such a way that my identity will not be physically attached to final data that I produce. The key linking my identity to the transcripts will be kept separate from the data in a locked file and will be destroyed when the research project is completed. All tapes, transcripts, memos, and research information will be kept in a separate locked file and will be destroyed when the research project is completed.

The general plan of the research project has been outlined to me. I understand that this research project will not involve risks of harm greater than those ordinarily encountered in daily life.

I understand that if at any time I have questions or would like clarification about the research project, I can contact Clark Sloan at 263-4558 or 220-7459.

(Date) (Signature) (Witness)

(Please Print Participant’s Name)
Figure 1

WORLD COLLAPSE

- Physical attributes
- Locus of control
- Pre-conceptions of disability
- Belief structure (religion)
- Coping skills

Pre-morbid Personality

- Family relations (childhood)
- Ego maturity
- Relationships—friendship
- Support system
- Age—wealth—education

LIVED EXPERIENCE

TRAUMA OF THE ACCIDENT

ORGANIC, BIOLOGICAL ISSUES
Loss of function of:
- Immune system and pain receptors
- Muscular system and movement
- Sensations for touch and hot and cold
- Bowel, bladder, and sexual ability
- Spinal Shock and Changes in ANS

ENVIRONMENTAL ISSUES IN INTENSIVE CARE & REHABILITATION
- Routinisation
- Desensitization and dehumanization
- Total vulnerability and helplessness
- Barriers including: time, money, energy, equipment, and architectural design

PSYCHOSOCIAL ISSUES OCCURRING IN INTENSIVE CARE & REHABILITATION
- Employment, relationships and friendships
- Role definition, status and prestige
- Possible future

NEGATIVE AFFECTIVITY
- Created dependency because people do too much for a person with SCI

THE LOOK
- Psychosocial stigmatisation of society
- Conceptualisation of self as incomplete
- Creates feelings of shame and guilt

NOCEBO EFFECT
- Negative placebo effect of the western medical model of health care instrumental in fostering a loss of hope

MISDIAGNOSIS OF DEPRESSION
- Same diagnostic criteria for depression, anxiety, bereavement, and drug toxicity

FILTER OF MEANING

BUFFERING EFFECT
- Trauma and excessive stress can trigger changes in the ANS that prevents the experiencing of emotions like anger or sexual loss

FROZEN IN TIME
- The person may become overwhelmed and automatically stores the affect and the pain of physical and psychological losses in the body and in the brain, frozen in time.

DENIAL
- Cognitively re-framing data for protection

PSYCHOLOGICAL ISSUES THAT OCCUR IN REHABILITATION
- Negative self talk
- Feelings of self as less or inadequate
- Feelings of being incomplete
- Feelings of shame or guilt
- Feelings of anger at self, God, or others
- Anxiety attacks because of paralysis
- Loss of feelings of self worth
- Loss of personal boundaries and identity
- Loss of hope for a future
- Loss of the meaning for living

SIGN OF AN INABILITY TO PROCESS PSYCHOLOGICAL ISSUES
- Obsessions—sex, drugs, work, and sports
- Nightmares and hallucinations
- Pressure of talk and phobias
- Sexual acting out and self mutilation
- Avoidance & overt expression of emotions

PSYCHOLOGICAL IMPLICATIONS OF INABILITY TO COPE WITH TRAUMA
- Disintegration of ego and self—esteem
- Separation of the mind, body, connection
- Fragmentation
- Dissociation

CRYSTALISATION
- Resort to pre-morbid coping skills and self-resources

ENTRY INTO COMMUNITY

World Collapse
Negative events such as an illness, death, loss of a job, or the loss of a relationship can trigger affect, stored in the brain and the body by the buffering effect of the ANS, caused by the trauma of SCI. The unresolved issues from the trauma, causing the affect, may be brought to consciousness allowing the person to become cognitively aware of the source of the affect. There may also be issues that were unresolved before the trauma. Once aware of the issues the healing process can begin.

The survival mode involves living exclusively in the here and now. Living one hour at a time—one day at a time—not thinking about the past or the future. Simply focusing on what you are doing at that moment. Survivors fill up their time with work, sports, relationships, hobbies, music, and TV. Anything that will fill the time so they won’t have to process their feelings and emotional affect. Survivors struggle to maintain the status-quo and often use coping skills and attributes which work effectively in the short term but do not work over time when new situations present themselves.
When a person with a SCI is experiencing World Collapse they resort to their pre-morbid coping skills. If these prove inadequate then the person may lose hope and escape by withdrawing and isolating themselves, using obsessive compulsive behaviour like drugs, alcohol and sex, self-mutilation, or overt expressions of emotions. Usually this leads to poor self-care of the skin, bladder and bowel. This accompanied by poor diet and hydration patterns leads to health complications and eventually a premature death because of self-neglect. Suicide rates for people with SCI are five to seven times greater than the normal population. It is estimated that as many as thirty five percent of the survivors of SCI die a premature death because of self-neglect.
The people with SCI who maintain their hope possess a deep and abiding will to live and succeed. They are flexible and use positive attributes and coping skills to create pathways to accomplish their goals. They take personal responsibility for their lives. They are patient, determined and won’t allow barriers to stop them. They possess high self-esteem and enter relationships based on worth and love and not on need. They realise that adjustment to SCI is a dynamic, ongoing lifelong process that requires them to change and adapt their coping style to adjust to new life situations that present themselves.
Figure 5
UNDERSTANDING THE TRAUMA OF SPINAL CORD INJURY © Sloan 2000
AVOIDANCE – Affect that has been repressed in the subconscious because of the buffering effect or denial is cognitively unavailable to consciousness - Frozen in Time.

INTRUSION – Individuals experience an event or a barrier that exceeds their innate tolerance and capacity to handle the new stress and it triggers the release of the stored affect.

DISEQUILIBRIUM – People's capacity to cognitively accommodate newly released affect is insufficient therefore they adopt inappropriate coping techniques - i.e., obsessions.

WINDOW OF THERAPEUTIC OPPORTUNITY
The counsellor's role is to help the client cognitively understand the cause of the emotional affect. If there is too much pain, then only emotion is experienced. If there is not enough pain, then there is no change. A balance of affect and cognitive understanding of its cause is required to desensitise the affect and have it absorbed. The counsellor needs to deal with exploration and consolidation, intensity content, and goal sequencing. The counsellor should be aware that pre-morbid issues like abuse or trust may be piggy backed onto the issues involved in the trauma of SCI.

ACTION – Clients should use hope in the form of desire and pathways to deal with the negative emotion. By changing the environment or by increasing or changing coping skills and attributes, they need to increase their tolerance and capacity to deal with the stressful situation and emotional release.

GROWTH – If Individuals take direct action, then they can absorb the affect and cognitively restructure their definition of themselves and experience a growth of their tolerance for stress. This cycle continues until affect is cognitively dealt with.